DOCUMENT RESUME

ED 143 183 EC 101 865

AUTHOR	Reggio, Kathryn D.
TITLE	Mental Health and Family Life Education. Individualized Health Incentive Program Modules for Physically Disabled Students for Grades Kindergarten Through Twelve. Teacher's Edition.
INSTITUTION	Human Resources Center, Albertson, N.Y.
SPONS AGENCY	Office of Education (DHEW), Washington, D.C.
BUREAU NO	H-233556
PUB DATE	77
GRANT	OEG-0-73-7065
NOTE	315p.
AVAILABLE FROM	Human Resources School, Albertson, New York 11507
EDRS PRICE	MF-$0.83 Plus Postage. HC Not Available from EDRS.
DESCRIPTORS	*Curriculum Guides; Elementary Secondary Education; *Family Life Education; Health Education; Maturation; *Mental Health; Personal Adjustment; Personal Growth; Physical Development; *Physically Handicapped; Problem Solving; Sex Education; State Curriculum Guides

ABSTRACT

Presented is a module in mental health and family life education adapted from the New York State Health Education curriculum to meet the needs of physically disabled students in grades K-12. It is explained that physically disabled students need to understand regular health habits in addition to special health concerns relating to their disability. An introductory section contains information on symptoms, hospitalization and treatment, and medical recommendations for nine types of disability, including muscular dystrophy and hemophilia. The bulk of the document is composed of listings of concepts, student activities, student self evaluations, and background information for teachers in four grade levels (sample topics in parentheses): grades K-3 (understanding the life cycle and human growth and development); grades 4-6 (the family as a social unit, personality, and growing toward the teen years); grades 7-9 (handling frustrations and solving problems, realistic goal planning, and dimensions of maturity); and grades 10-12 (learning how other disabled people succeeded, problems of sexual and reproductive ability, and experiences in child care). (CL)

****
* Documents acquired by ERIC include many informal unpublished *
* materials not available from other sources. ERIC makes every effort *
* to obtain the best copy available. Nevertheless, items of marginal *
* reproducibility are often encountered and this affects the quality *
* of the microfiche and hardcopy reproductions ERIC makes available *
* via the ERIC Document Reproduction Service (EDRS). EDRS is not *
* responsible for the quality of the original document. Reproductions *
* supplied by EDRS are the best that can be made from the original. *
****

ED143183

U.S. DEPARTMENT OF HEALTH, EDUCATION & WELFARE
NATIONAL INSTITUTE OF EDUCATION

THIS DOCUMENT HAS BEEN REPRODUCED EXACTLY AS RECEIVED FROM THE PERSON OR ORGANIZATION ORIGINATING IT. POINTS OF VIEW OR OPINIONS STATED DO NOT NECESSARILY REPRESENT OFFICIAL NATIONAL INSTITUTE OF EDUCATION POSITION OR POLICY

Mental Health and Family Life Education

INDIVIDUALIZED HEALTH INCENTIVE PROGRAM MODULES FOR PHYSICALLY DISABLED STUDENTS FOR GRADES KINDERGARTEN THROUGH TWELVE

TEACHER'S EDITION

Kathryn Reggio, Ph. D., *Project Director*
Josephine Davidson, R. N., M. S., *School Nurse - Teacher*
Donna Shooltz, M. L. S., *Research Associate*

HUMAN RESOURCES SCHOOL
ALBERTSON, NEW YORK 11507
1977

Richard M. Switzer
Project Administrator | Headmaster

"PERMISSION TO REPRODUCE THIS COPYRIGHTED MATERIAL BY MICROFICHE ONLY HAS BEEN GRANTED BY

Kathryn D. Reggio

TO ERIC AND ORGANIZATIONS OPERATING UNDER AGREEMENTS WITH THE NATIONAL INSTITUTE OF EDUCATION. FURTHER REPRODUCTION OUTSIDE THE ERIC SYSTEM REQUIRES PERMISSION OF THE COPYRIGHT OWNER."

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

Kathryn D. Reggio

Lucas II

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC) AND THE ERIC SYSTEM CONTRACTORS."

EC101865

Grant No. OEG-O-73-7065
Project No. H 233556

The project presented herein was performed pursuant to a grant from the U. S. Office of Education, Department of Health, Education, and Welfare. However the opinions expressed herein do not necessarily reflect the position or policy of the U. S. Office of Education, and no official endorsement by the U. S. Office of Education should be inferred.

FOREWORD

I am delighted to congratulate the distinguished members of the Human Resources School faculty whose efforts and dedication over the last three years have culminated in the publication of these Health Education modules.

Health Education is one of the most important components of any school's curriculum. It is not enough for us to prepare our children to enter college or the world of work; we must prepare them to enter the arena of life equipped with a full understanding of their bodies and minds. Topics like mental health, family life, safety, and nutrition are as important to the growing disabled child as they are to the able-bodied youngster.

My responsibilities as Chairman of the White House Conference on Handicapped Individuals have given me a clear perspective on the status of the severely disabled in America's communities. Throughout the nation, states are enacting legislation to mainstream disabled children into neighborhood public schools. The modules will go a long way in preparing teachers in public schools in New York State and throughout the country to provide handicapped children with a proper health education.

Henry Viscardi, Jr.
Human Resources Center

ACKNOWLEDGMENTS

I would like to acknowledge with special appreciation the extraordinary contributions of the project team: Josephine Davidson, Donna Shooltz, Marilyn Hawkins, Dr. Leon Greenspan, Dr. Ronald Friedman, and Harriet Findlay.

Special recognition goes to the dedicated faculty members who contributed activities, worked with the students, evaluated, and revised these modules: Barbara Steinberg, Eileen Singleton, Barbara Ringewald, Edna Humbert, Kathy Finnigan, Susan Gordon, Patricia Iannucci, Jeanne Kuskowski, Carol D'Ambrosio, Rose Grabelsky, Marion Seidman, William Lupardo, and Sheila Mohrman.

Gratitude is expressed to our guest speaker-consultants who generously shared their experiences and advice with our students: Richard Switzer, Arthur Nierenberg, Robert Gibney, Daniel Sullivan, Lorraine Bertan, William Engels, Cathy Burke, Veronica McSherry, Dr. Marie Meier, Irving Hammerschlag, Speakers from Alcoholics Anonymous and Al-a-teen, Dr. James Mucri, Dr. Emanuel Plesent, Evelyn Kolonoski, Frank Gentile, and Dr. Henry Viscardi.

Special appreciation is extended to the research librarian, Ruth Velleman, for resourcefulness and zeal in obtaining all the specialized books, articles, and curriculum guides used by the project staff and the students.

Sincere thanks goes to the capable and zealous project secretaries, Susan Kurtzke and Marie Bennett.

For invaluable guidance in the technicalities of developing our project, I wish to add a note of appreciation to Dr. Edwin Martin, Dr. Max Mueller, and Melville Appell of the Bureau of Education for the Handicapped.

The wholehearted cooperation of the New York State Education Department and their division of Health and Drug Education gave the basis for this work and the impetus to bring it to completion. Their cooperation is gratefully acknowledged.

A final note of thanks must be expressed for the cooperative involvement and constant encouragement of our administrators, Richard Switzer, Dr. Henry Bormann, and Robert Gibney.

Kathryn D. Reggio
Project Director

TABLE OF CONTENTS

Foreword i

Acknowledgments ii

Introduction 1

Definitions of Disabilities 4

Summary of Information about Disabilities 6

Mental Health and Family Life Education Activities for Elementary Students 17

Mental Health and Family Life Education Activities for Secondary Students 19

Evaluation 24

MENTAL HEALTH AND FAMILY LIFE EDUCATION MODULES

Grades K-3 – Special Topics and Objectives 29
I. The Family As a Social Unit 30
A. Children's Role 30
B. Parents' Role 31

II. Understanding the Life Cycle 32
A. Male and Female Gender 32
B. Meaning of Reproduction 32
C. Parents' and Child's Role in Caring for Babies 33

III. Human Growth and Development 34
A. Physical Development and Body Image 34
B. Social Development and Friendship 36

Grades 4-6 – Special Topics and Objectives 40
I. The Family as a Social Unit 41

II. Role Arrangements in Family Life 42
A. Role Identity 42
B. Human Reproduction 43

III. Personality 45
A. Positive Attitude and Positive Self-Concept 45
B. Improving Personality through Communication 47
C. Experiencing Independence 49
D. "Modeling" – Learning from Older Disabled Students .. 50

IV. Growing Toward the Teen Years 51
A. Individual Patterns of Physical, Social, and Emotional Development 51
B. Peer Relationships 53

Grades 7-9 – Special Topics and Objectives 57
I. Why We Do the Things We Do 58
A. Positive Self-Concepts 58
B. Handling Frustrations and Solving Problems 58
C. Using Leisure Time to Promote Well-Being 60

II. Learning More About Ourselves 61
A. Teen-Age Concerns 61
B. Values 62
C. Realistic Goal-Planning 65

III. Dimensions of Maturity 68
A. Physical Maturity and Adolescent Development 68
B. Emotional Maturity 70
1. Communicating 70
a. Asking and Refusing Help 70
b. Educating Others About Disability 70
2. Attitudes Toward Oneself and Others 72
3. Making and Keeping Friends 74
4. Accepting Responsibility 75

IV. Interpersonal and Boy-Girl Relationships During Adolescence . 76

Grades 10-12 – Special Topics and Objectives 79
I. Personality Development 80
A. Self-Concept and Emotional Health 80

(continued)

MENTAL HEALTH AND FAMILY LIFE EDUCATION MODULES

B. Motivation – Learning How Other Disabled People Succeeded 82
C. Structured Leisure Time 85
D. Death 87

II. Sexuality 89
A. Dating 89
B. Problems of Sexual and Reproductive Ability 91
C. Human Development and Disability Occurrence 94
1. Fetal Development and Disability Occurrence 94
2. Heredity – Its Influence on Certain Disabilities 95

III. Family Life Education 96
A. Understanding One's Parents 96
B. Preparing for Responsible Independence 97
C. Single or Married Adult Life 99
D. Experiences in Child Care 100

Appendix 104
New York State Curriculum Outline 104
Helpful Teacher References 108
Annotated Bibliography for Specific Disabilities 112

INTRODUCTION

The purposes of this project are to adapt the New York State Health Education curriculum to the special needs of physically disabled students in grades kingergarten through twelve, and to organize educational information about physical disability.

This module, Mental Health and Family Life Education, is one of the five areas or strands of health education which have been adapted. The others are Safety and Survival Education, Physical Health, Sociological Health Problems, and Environmental and Community Health.

Under each topic of the New York State Health Education curriculum, individualized health incentive program modules have been adapted for students having the physical disabilities included at Human Resources School.

To deal with the mental health needs of children in the school whose disabilities included 33 different handicaps or diseases, this adapted curriculum considers them under nine broad categories of health problems.

1. Lack of function of the involuntary nervous system
2. Diminution or absence of feeling in the extremities, paralysis, wearing braces, confinement to a wheelchair, poor cordination
3. Generalized muscle weakness
4. Arm and joint immobility
5. Prosthetic limbs
6. Fragility of bones
7. Diminutive size
8. Poor circulation
9. Inability to control bleeding

Each health problem is represented by the underlined disability listed next to it, but it is felt that the modules could also apply to the other disabilities which are listed with the underlined disability.

Thus, teachers and students could use the activities of the module for any of the other disabilities in the same category.

This program builds in the incentive by incorporating student self-evaluation activities and a number of motivational procedures. It is believed that student self-evaluation based on individually chosen relevant learning activities provides the greatest incentive for learning and leads to a stronger desire to improve.

The three columns on each right-hand page are directed toward the student, and the student activities and self-evaluations are written in terms of behavioral objectives. Only the teacher's module contains the background information on the left-hand page.

Dysautonomia

Spina Bifida, Post-poliomyelitis, Quadraparesis, Paraplegia, Hemiplegia, Spastic Paraplegia, Dystonia, Legg-Calve-Perthes Disease, Seizure Disorders

Muscular Dystrophy, Amyotonia Congenita, Kugelberg-Welander Disease, Charcot-Marie-Tooth Disease

Arthrogryposis, Rheumatoid Arthritis

Congenital Amputee, Limb Deformities

Osteogenesis Imperfecta

Achondroplasia

Congenital Cardiac Conditions, Rheumatic Heart Disease

Hemophilia, Thalassemia, Sickle Cell Disease

This curriculum is conceived of as separate modules for each topic. It has been printed and bound in two forms – the first, a limited number of the separate modules, and the second with the modules combined into bound booklets. This second form was necessitated by budgetary limitations. Human Resources accepted the responsibility of sharing the finished product with all the participating agencies, school districts, and consultants who cooperated with the committee during the project's development. This was possible only by binding the modules as booklets instead of packaging each one separately in its own packet or binder.

The suggested method of use is to have each student individually choose the topic he finds pertinent and follow the related activities and student self-evaluations.

The student's modules can be printed without the teacher background information.

The activities were designed for use with the severely physically disabled students at Human Resources School. The school has certain decided advantages for implementing a special health education curriculum:

1. A number of students with similar disabilities who can work together on related activities.

2. Accommodated rooms, furniture, shelves, elevators, automated doors, etc.

3. Specially adapted: library, swimming pool, gymnasium, stage, auditorium, cafeteria, art room, toilets, open classroom, home economics room, greenhouse.

4. Services of a physician, school-nurse-teacher, practical nurse, physical therapist, dental clinic, orderly, psychologist, speech therapist, and 200 volunteers.

5. Equipment: motorized wheelchairs, rolling litters, rolling stretchers.

The staff of the school has found that students who might otherwise be homebound can be physically accommodated. When the physical accommodations are provided, the intellectual and social needs can be taken care of. The health project committee does believe that, although it was developed in a special setting, this health curriculum also has a wider application to schools or classes having only a few students with physical disabilities.

Although the average school may not have all the suggested accommodations, the background information pages tell the teachers what their students with certain disabilities might be expected to do and what special needs must be considered in their health education.

School districts wishing to conform to the law mandating equal opportunity for education for the handicapped may be able to adapt their facilities on a smaller scale as the needs arise.

In inaugurating a health curriculum at Human Resources School, a great deal of time had to be spent on the most basic general material. For a number of reasons, the students at Human Resources School knew less about health than the average student.

The opportunity to spend more time than the minimal amount required by the state had never presented itself before. Students had missed a great deal of both academic and health education through long absences and hospital stays. The fact that someone else had had to perform a great deal of their physical care had made it unnecessary to learn basic hygiene or health habits. This situation had also delayed or discouraged the development of individual initiative.

The curriculum in mental health recommended for physically disabled students and followed as a basic course at Human Resources School includes the content topics given in the New York State Health Education Curriculum. We feel that they are excellent. As a matter of fact, our experience has been that our students needed a great deal more time devoted to the content than was required by the state – and we did allow the necessary time.

The basic assumption at Human Resources School is that our students are normal young people who happen to have a disability. They have all the physical, emotional, and intellectual needs of other normal students, plus some additional ones engendered by their disability. We therefore regard our curriculum as an addition to the New York State curriculum, not a replacement, and recommend that both the basic course of study for New York State, and the units developed at Human Resources School be used together.

A curriculum in health education for physically disabled, intellectually average students should include all the knowledge and topics in the regular curriculum so that disabled students with limited experience will be able to understand the standards of the average, physically "normal" person and can

realize how much of their own health and bodily activity is the same as that of the average person.

Because of their limited experience or sheltered environment, some physically disabled students need special understanding about how and why regular health habits apply to them.

In addition, physically disabled students need to learn the practicalities of dealing with special health problems related to or resulting from their disability. As a matter of fact they need to learn what their disability is, and to know how to maintain or improve their health status.

Conclusion: They need more time for health education. The recommendation is for six half-year programs in junior-senior high school on a 3-year cycle of topics, 3 for junior high and 3 for senior high.

In each of the elementary grades, integration with other subjects is recommended on a three-times-a-week basis.

DEFINITIONS OF DISABILITIES

DYSAUTONOMIA – Genetic condition found in Jewish children of Eastern European extraction. Affects the function of the autonomic (involuntary) nervous system. Skeletal involvement, such as scoliosis, often occurs.

SPINA BIFIDA – Congenital (existing from birth). Defect in the vertebral column characterized by the presence of a myelomenigocele (protrusion of the spinal cord and membrance covering it) both of which should normally be covered by vertebrae. Below the level of the defect, the child has diminished sensation of lower extremities, varying degrees of paralysis, and is incontinent of bowel and bladder.

POST-POLIOMYELITIS – Poliomyelitis is an infectious disease affecting the motor cells in the spinal cord resulting in weakness or paralysis. There may be subsequent atrophy of groups of muscles, ending in contraction and permanent deformity.

QUADRIPLEGIA – Paralysis affecting all four extremities.

PARAPLEGIA – Paralysis of lower portion of body – below waist. May be traumatic, infectious, or congenital.

HEMIPLEGIA – Paralysis on one half of the body – one leg and arm on one side.

SPASTIC PARALEGIA – Spastic paralysis occuring in early childhood. May be traumatic, infectious or congenital. May involve cerebral hemorrhage before birth, or abnormal, involuntary movements of the muscles.

DYSTONIA – Musculorum Deformans – Chronic motor disorder. May be hereditary. Marked by abnormal movements of the muscles.

ATAXIA – Generalized term – usually involves poor coordination, lack of dexterity, unsteady gait, and slow speech. May be congenital or acquired.

FRIEDRICH'S ATAXIA – Progressive paralysis of lower limbs, ataxia and speech impairment.

LEGG-CALVE-PERTHES DISEASE – A disease of the head of the thigh bone which causes a degeneration and necrosis. This is followed by regeneration or recalification. (hip area). Most often affecting boys between four and eleven years of age.

CEREBRAL PALSY – The most common terminology used for children whose symptoms are similar to those with Ataxia. However, there is also a disorder in movement, posture, and coordination related to non-progressive damage to the brain.

MUSCULAR DYSTROPHY – (Duchenne) Hereditary disorder transmitted by females but affecting mostly males. Progressive generalized weakness of the voluntary muscles. Non-contagious, chronic wasting which leads to increasing infirmity, and ultimately death.

AMYOTONIA CONGENITA (Oppenheim's Disease) – Born with generalized poor muscle tone. "Floppy" With or without muscle weakness. A descriptive term for many conditions. (Spinal Atrophy)

KUGELBERG-WELANDER DISEASE – A Neuro-muscular disorder. Weakness and atrophy (wasting) of muscles; slowly progressive.

CHARCOT-MARIE-TOOTH DISEASE – Peroneal muscular atrophy. Hereditary meuro-muscular disorder. Slowly progressive muscle atrophy and weakness, starting in the legs.

ARTHROGRYPOSIS MULTIPLEX CONGENITA – A congenital, non-progressive condition in which the tissues at some or all the joints are stiff and fibrous holding the limbs rigid in flexed or extended positions. The joint malformations result from immobilization of the developing embryo from any of a variety of causes which prevent normal spontaneous movements.

RHEUMATOID ARTHRITIS – Disease in which inflamed joints are often accompanied by pain, swelling, and limitations in joint movement and weakness of muscles.

CONGENITAL AMPUTEE – Children who are born with total or partial absence of a limb. (Also called reduction deformity)

LIMB DEFORMITIES – Distortion or disfigurement of a limb.

OSTEOGENESIS IMPERFECTA – This condition, also known as "Brittle Bones", is an inherited disorder of development in the skeleton in which the calcium content is far below normal. The bones are excessively thin and subject to multiple fractures following even mild trauma. Children are usually smaller in stature because fractures often occur in the long bones of lower extremities. Congenita: born with abnormalities and often many fractures. Tarde: Condition often not seen until the child starts to walk. Then fractures occur.

ACHONDROPLASIA – Congenital, frequently hereditary disorder in the conversion of cartilage to bone. Because of this, the growing ends, or epiphyses, of the long bones of the limbs, are affected, and inadequate growth results in a type of dwarfism. Short extremities, but well proportioned body. Lordosis (curvature of spine) often occurs, too.

CONGENITAL CARDIAC CONDITIONS – Born with a defect of the heart. This may involve a defect of the valves or it may involve the great vessels. Some of these can be corrected by surgical procedures.

RHEUMATIC HEART DISEASE – Injures the endocardium, the valve, or the muscle fibers. The valves may lose their original efficiency, so that passage of blood is hindered.

HEMOPHILIA – Hereditary disorder transmitted by females but usually affecting only males. An abnormality in blood coagulation resulting in prolonged coagulation time and lowered prothrombin (clotting factor II) consumption.

THALASSEMIA – Hereditary; genetically determined, chronic anemia, causing poor bone growth, fatigability, nose bleeds, and low grade fever.

SICKLE CELL DISEASE – A hereditary, genetic condition of the blood which affects the red blood cells causing them to be malformed like a sickle. Occurs most often in blacks. Characterized by arthralgia, acute attacks of abdominal pain, and ulcerations of the lower extremities.

SUMMARY OF INFORMATION ABOUT DYSAUTONOMIA (1)

For the general understanding of teachers or aides who might be working with a student with this disability, we have compiled a general summary from the records of the students at Human Resources School. This information represents a variety of findings, since each student has his own physician and may have attended different hospitals or rehabilitation centers.

Therefore, two important points must be noted. One is that each child is different, and so is the severity of his disability. The other is that medical procedures and recommendations are constantly advancing and changing, and these findings represent only a summary of the past.

Dysautonomia – Genetic condition found in Jewish children of Eastern European extraction. Effects function of autonomic (involuntary) nervous system. Skeletal involvement, such as scoliosis, often occurs.

SYMPTOMS:

Lack of tears

Insensitivity to pain

Vomiting

Blotching of skin

Unstable temperature – fluctuations unrelated to infections

Unstable blood pressure

Emotional instability

Delayed development (Riley-Day Syndrome: late motor development, floppy appearance, tendency to vomit, some degree of pseudo-retardation due to lack of experience and exposure early in life)

HOSPITALIZATIONS AND TREATMENTS:

Nerve biopsies (nerves have areas without normal bundles)

Eyes: histamine and mecalin

SPECIAL PROBLEMS NOTED AND RECOMMENDATIONS MADE BY DOCTORS:

PROBLEMS:

Corneal ulcers

Gastro-intestinal problems

Bladder problems – incontinence of urine

Skeletal system: scoliosis, deformities of long bones, embarrassment of respiratory system

Tendency to become fatigued easily because of weaker muscles, diminished respiratory function, lower endurance

Sleep often interrupted by URI or vomiting

Short life expectancy – death possible from aspiration, cardiac or respiratory failure, high fever, fluctuating blood pressure

RECOMMENDATIONS:

Therapy: derotation exercises for scoliosis, ROM and active assistive exercises, breathing exercises

Back brace if scoliosis is severe

Artificial tears to be administered several times daily

Quiet firmness on the part of teachers and others in authority; need for defined controls and limits

SUMMARY OF INFORMATION ABOUT SPINA BIFIDA MANIFESTA (2)

For the general understanding of teachers or aides who might be working with a student with this disability, we have compiled a general summary from the records of the students at Human Resources School. This information represents a variety of findings, since each student has his own physician and may have attended different hospitals or rehabilitation centers.

Therefore, two important points must be noted. One is that each child is different, and so is the severity of his disability. The other is that medical procedures and recommendations are constantly advancing and changing, and these findings represent only a summary of the past.

Spina Bifida Manifesta – Congenital (existing from birth). Defect in the vertebral column characterized by the presence of a myelomeningocele (protrusion of the spinal cord and membranes covering it) both of which should normally be covered by vertebrae. Below the level of the defect, the child has diminished sensation of lower extremities, varying degrees of paralysis, and is incontinent of bowel and bladder.

SYMPTOMS:

Myelomeningocele present at birth

Sensory loss and motor loss

Bowel and bladder incontinence

Hydrocephalus (enlargement of the head caused by improper circulation and absorption of cerebrospinal fluid) may develop any time after birth.

HOSPITALIZATIONS AND TREATMENTS NOTED IN RECORDS:

Closure of myelomeningocele shortly after birth

Shunt procedure to redirect cerebrospinal fluid into the heart, where it can circulate with the blood and reduce the possibility of hydrocephalus.

Periodic shunt revisions later in life

Periodic urological check-ups

SPECIAL PROBLEMS NOTED AND RECOMMENDATIONS MADE BY DOCTORS:

PROBLEMS:

Occasional tenderness at area of myelomeningocele closure

Development of decubitus ulcers on buttocks

Pressure sores from braces

Development of lower extremity deformities

Urinary tract infections

RECOMMENDATIONS:

Therapy: ROM, PRE for uppers, ambulation training with appliances, swimming

Brace changes

Surgical procedures to allow ambulation without braces

Treatment of decubitus ulcers

SPECIAL PROBLEMS NOTED AND RECOMMENDATIONS MADE BY PARENTS:

Change in behavior after shunt revisions

Embarrassment at bowel and bladder incontinence

Embarrassment at wearing orthopedic shoes (noted by teacher)

SUMMARY OF INFORMATION ABOUT MUSCULAR DYSTROPHY (3)

For the general understanding of teachers or aides who might be working with a student with this disability, we have compiled a general summary from the records of the students at Human Resources School. This information represents a variety of findings, since each student has his own physician and may have attended different hospitals or rehabilitation centers.

Therefore, two important points must be noted. One is that each child is different, and so is the severity of his disability. The other is that medical procedures and recommendations are constantly advancing and changing, and these findings represent only a summary of the past.

Duchenne Muscular Dystrophy – Hereditary disorder transmitted by females but affecting mostly males. Progressive generalized weakness of the voluntary muscles. Non-contagious, chronic wasting which leads to increasing infirmity, and ultimately death.

MEDICAL LISTING OF EIGHT STAGES OF FUNCTIONAL ABILITY

1. Ambulates with waddling gait and marked lordosis. Elevation activities adequate (climbs stairs and curbs without assistance).
2. Ambulates with waddling gait and marked lordosis. Elevation activities deficient (needs support for curbs and stairs).
3. Ambulates with waddling gait and marked lordosis. Cannot negotiate curbs or stairs, but can achieve erect posture from standard height chair.
4. Ambulates with waddling gait and marked lordosis. Unable to rise from a standard chair.
5. Wheelchair-independence: Good posture in the chair, can perform all activities of daily living from wheelchair.
6. Wheelchair-dependence: Can roll chair, but needs assistance in bed and wheelchair activities.
7. Wheelchair-dependence-and back support: Can roll the chair only a short distance, needs back support for good wheelchair position.
8. Bed Patient: Can do no activities of daily living without maximum assistance.

SUMMARY OF FINDINGS FROM SCHOOL RECORDS

For the general understanding of teachers or aides who might be working with a student with Muscular Dystrophy we have summarized the findings of the records of our 34 students who have Muscular Dystrophy.

EARLY STAGES–

SYMPTOMS–

Ambulates with moderate amounts of waddling and lordosis (bending backwards) with a heel-toe pattern

Ability to walk on toes but not on heels

Need to use rail or have assistance in going up stairs or climbing a curb

Complete independence in all activities of daily living

Deep tendon reflexes absent except for Achilles jerk

Normal range of motion except for tight heel cords

Bilateral hypertrophy of the calf

Tendency to fall frequently

SPECIAL PROBLEMS NOTED AND RECOMMENDATIONS MADE BY DOCTORS

Encouragement to ambulate as much and as long as possible to prevent progression of deformities

Therapy–Active assistive exercies for upper extremities, exercises for trunk musculature, ROM (Range of Motion) of hips, knees, and ankles. All to prevent later deformities and to help maintain present level of function.

Lengthening of the heel cord and transplanting of tibial dorsum to allow ambulation for a longer period of time. (Can ambulate with braces or cast one week following surgery.)

MIDDLE STAGES–

SYMPTOMS–

Increased tendency to fall and inability to get up after falling

Final confinement to a wheelchair and dependence for activities of daily living except for feeding self and writing

Development of flexion contractures of both hips and knees and equinovarus deformity of ankles.

Severely limited range of motion in heel cord

Development of scoliosis (curvature of the spine)

Absence of deep tendon reflexes except for achilles jerk

Tendency to obesity

SPECIAL PROBLEMS NOTED AND RECOMMENDATIONS MADE BY DOCTORS–

Continuation of therapy to maintain level of function and prevent further deformities

Sometimes braces to prevent deformities

Wheelchair when ambulation is no longer possible

Diet to control obesity

Disruptive behavior in school sometimes noted by parents and teachers

LATER STAGES–

SYMPTOMS–

Complete dependence in all activities of daily living

Inability to feed self or write as musculature of wrists and hands decreases

Round facial appearance with involvement of muscles of mastication (chewing)

Complete absence of deep tendon reflexes

Progression of hip, knee and ankle deformities

Tendency to obesity

SPECIAL PROBLEMS NOTED AND RECOMMENDATIONS MADE BY DOCTORS–

Appliance to aid in writing and feeding self

Plastic sitting corset to prevent progression of scoliosis

Electric wheelchair

Diet to control obesity

Comfort aids, particularly specially made cushions to prevent pressure sores on buttocks

HOSPITALIZATIONS NOTED IN RECORDS–

Sometimes surgery for lengthening of heel cord (early stages)

Respiratory infections (later stages)

MEDICAL TREATMENTS NOTED IN RECORDS–

Surgical lengthening of the heel cord and transplanting of the tibial dorsum to allow ambulation for a longer period of time

Inhalation therapy

TESTS NOTED IN RECORDS–

Muscle biopsy, enzyme studies, etc. to determine carrier

Blood tests of parents to determine if disability is result of mutation or sex-linked characteristic

SUMMARY OF INFORMATION ABOUT ARTHROGRYPOSIS MULTIPLEX CONGENITA (4)

For the general understanding of teachers or aides who might be working with a student with this disability, we have compiled a general summary from the records of the students at Human Resources School. This information represents a variety of findings, since each student has his own physician and may have attended different hospitals or rehabilitation centers.

Therefore, two important points must be noted. One is that each child is different, and so is the severity of his disability. The other is that medical procedures and recommendations are constantly advancing and changing, and these findings represent only a summary of the past.

Arthrogryposis Multiplex Congenita – A congenital, non-progressive, condition in which the tissues at some or all the joints are stiff and fibrous, holding the limbs rigid in flexed or extended positions. The joint malformations result from immobilization of the developing embryo from any of a variety of causes which prevent normal spontaneous movements.

SYMPTOMS:

Underdeveloped due to basic disability; generalized underdevelopment of muscles and resultant muscle weakness

Absence of deep tendon reflexes

From birth – Flexion deformities of the hips, knees, wrists, toes; deformities of feet; dislocated hips

HOSPITALIZATIONS AND TREATMENTS:

Surgery to correct flexion deformities

Heel cord lengthenings and tissue releases

Bone fusions

Casting of hand to improve function (done when young)

SPECIAL PROBLEMS NOTED AND RECOMMENDATIONS MADE BY DOCTORS:

PROBLEMS:

Development of scoliosis

Frequent abdominal complaints due to ulcers or ulcerated colitis (young adults)

Little functional use of hands – need for assistance in ADL's

RECOMMENDATIONS:

Braces – standing and ambulation with appliances if possible

Sitting corset for scoliosis (to prevent further progression)

Orthopedic devices for feeding and writing

No contra-indication for swimming

Therapy: Range of motion for all joints; active assistive exercises for uppers

Wheelchair for distance if necessary

SPECIAL PROBLEMS NOTED AND RECOMMENDATIONS MADE BY PARENTS:

Assistance for ADL's

Daily therapy at home

Sitting corset difficult to handle

Pressure sores from braces

Rheumatoid Arthritis – Disease in which inflamed joints are often accompanied by pain, swelling, and limitations in joint movement and weakness of muscles.

SYMPTOMS

EARLY STAGES

Fatigue, muscular stiffness, loss of appetite and weight, cold hands and feet, swelling of joints, nodules on skin.

LATER STAGES

Loss of joint motion resulting in flexion deformities and limitation in range of movement.

HOSPITALIZATIONS AND TREATMENTS

PHYSICAL THERAPY – ROM, active assistive exercises, progressive resistive exercises

Possible splinting of hands or other surgical measures

DRUGS – Aspirin, steroids (group of drugs related to cortisone which may be discontinued because of undesirable side effects), gold salts, and antimalarials (may bring about remissions after several months of treatment).

SPECIAL PROBLEMS NOTED AND RECOMMENDATIONS MADE BY DOCTORS:

PROBLEMS:

Limitation in ADL, even restricting feeding and writing in some cases

RECOMMENDATIONS:

Diet, posture, avoidance of colds and dampness

No contra-indication for swimming

SUMMARY OF INFORMATION ABOUT CONGENITAL AMPUTEES (5)

For the general understanding of teachers or aides who might be working with a student with this disability, we have compiled a general summary from the records of the students at Human Resources School. This information represents a variety of findings, since each student has his own physician and may have attended different hospitals or rehabilitation centers.

Therefore, two important points must be noted. One is that each child is different, and so is the severity of his disability. The other is that medical procedures and recommendations are constantly advancing and changing, and these findings represent only a summary of the past.

Congenital Amputee – Children who are born with total or partial absence of a limb. (Also called reduction deformity).

HOSPITALIZATIONS AND TREATMENTS:

Depending on extent of deformity, prosthetic limbs are fitted.

Sometimes a surgical procedure may be done to facilitate fitting of a prosthetic.

As the child grows, new fittings are necessary so there is a possibility of repeated hospitalizations throughout their lives.

SPECIAL PROBLEMS AND RECOMMENDATIONS MADE BY DOCTORS:

Make sure area of limb that fits into prosthesis is protected from skin breakdown.

When prosthesis gets too small rubbing can cause skin irritation.

Use these prostheses.

SUMMARY OF INFORMATION ABOUT OSTEOGENESIS IMPERFECTA (6)

For the general understanding of teachers or aides who might be working with a student with this disability, we have compiled a general summary from the records of the students at Human Resources School. This information represents a variety of findings, since each student has his own physician and may have attended different hospitals or rehabilitation centers.

Therefore, two important points must be noted. One is that each child is different, and so is the severity of his disability. The other is that medical procedures and recommendations are constantly advancing and changing, and these findings represent only a summary of the past.

Osteogenesis Imperfecta – This condition, also known as "Brittle Bones", is an inherited disorder of development in the skeleton in which the calcium content is far below normal. The bones are excessively thin and subject to multiple fractures following even mild trauma. Children are usually smaller in stature because fractures often occur in the long bones of the lower extremities

Congenita: born with abnormalities and often many fractures.

Tarde: condition often not seen until the child starts to walk. Then fractures occur.

SUMMARY OF FINDINGS FROM SCHOOL RECORDS:

For the general understanding of teachers or aides who might be working with a student with Osteogenesis Imperfecta, we have summarized the findings of the records of our 14 students who have Osteogenesis Imperfecta.

SYMPTOMS:

Eyes – Blue Sclera

Teeth translucent with pearl-like appearance

Healed fractures, primarily of lower extremities

Bowing of long bones (Shepherd's Crook)

Short structure – disproportion between trunk and extremities due to frequent fractures

Megacephaly only apparent because of trunk size as seen in proportion to extremities

Generally underdeveloped physical appearance

Infantile behavior due to protection necessitated by brittle bones – infantile behavior in young children.

HOSPITALIZATIONS:

Fractures – some set in doctor's office; others requiring surgery

Rodding of femur and tibia to aid in the prevention of further fractures (some cases)

MEDICAL TREATMENTS NOTED IN RECORDS:

Calcitonin – Some cases

Therapy (various depending on each child)

A. Swimming
B. Ambulation training if possible
C. Exercise for ROM, muscle strength, etc.

SPECIAL PROBLEMS NOTED AND RECOMMENDATIONS MADE BY DOCTORS:

Limitations set on Physical Education Activities

Fear of doctors and examinations

Immaturity and infantile behavior

Recommendations for therapy, rodding procedures, change in appliances or wheelchairs

SPECIAL PROBLEMS NOTED AND RECOMMENDATIONS MADE BY PARENTS:

Fear of doctors

Fear of falling

Fear of fractures

Discomfor while in SPICA

Fear of being handled by people other than parents

SUMMARY OF INFORMATION ABOUT ACHONDROPLASIA (7)

For the general understanding of teachers or aides who might be working with a student with this disability, we have compiled a general summary from the records of the students at Human Resources School. This information represents a variety of findings, since each student has his own physician and may have attended different hospitals or rehabilitation centers.

Therefore, two important points must be noted. One is that each child is different, and so is the severity of his disability. The other is that medical procedures and recommendations are constantly advancing and changing, and these findings represent only a summary of the past.

Achondroplasia – A congenital disorder due to the conversion of cartilage to bone (frequently hereditary). Because of this, the growing ends or epiphyses, of the long bones of the limbs, are affected, and inadequate growth results in a type of dwarfism. Short well-porportioned body. Lordosis (curvature of the spine) often occurs, too.

SYMPTOMS:

Small size

Average achondroplastic attains a height of 50". Head is apt to be enlarged, although it appears relatively larger than it is because of small body size. Often bowing appearance to the legs.

Life expectancy is fairly normal.

HOSPITALIZATIONS AND TREATMENTS:

As they develop into middle life complications might possibly develop from their lordosis (abnormal curvature of the spine).

SPECIAL PROBLEMS NOTED AND RECOMMENDATIONS MADE BY DOCTORS:

Biggest problem is adapting to a world of "normal" size people and being able to function in a world made for "normal" size people. This affects schooling, socialization, and employment opportunities.

SUMMARY OF INFORMATION ABOUT CONGENITAL CARDIAC CONDITIONS (8)

For the general understanding of teachers or aides who might be working with a student with this disability, we have compiled a general summary from the records of the students at Human Resources School. This information represents a variety of findings, since each student has his own physician and may have attended different hospitals or rehabilitation centers.

Therefore, two important points must be noted. One is that each child is different, and so is the severity of his disability. The other is that medical procedures and recommendations are constantly advancing and changing, and these findings represent only a summary of the past.

Congenital Cardiac Conditions – born with a defect of the heart. This may involve a defect of the valves or it may involve the great vessels. Some of these can be corrected by surgical procedures.

SYMPTOMS:

In some heart conditions children have cyanotic or bluish coloring to lips and nail beds, caused by lack of oxygen in blood stream.

Shortness of breath following a period of exertion

Generally smaller in stature

HOSPITALIZATIONS AND TREATMENTS:

Correction of defect

Treatment of complications of defect

Treatment of severe respiratory infection which might cause difficulty in breathing.

Often hospitalized for procedure to improve condition of blood.

Examinations of the heart (eg., catheterizations) to define exact area of defect.

SPECIAL PROBLEMS NOTED AND RECOMMENDATIONS MADE BY DOCTORS:

More susceptible, probably to upper respiratory infections because of the way the body is affected by poor circulation and because of connection between heart and lungs.

Enlarged heart is common, because heart has to work twice as hard to accomplish its work.

Insufficiency of oxygen to brain may cause learning problems.

Problems related to circulation.

Extremes of temperature lower body resistance to infection. Therefore, air-conditioned building is better because temperature is more even.

May need to be more careful about overdoing.

Children with congenital heart disease are usually self-limiting in what they are able to do. This separates them from those who have an acquired heart disease and must be made to slow down and rest.

SUMMARY OF INFORMATION ABOUT HEMOPHILIA (9)

For the general understanding of teachers or aides who might be working with a student with this disability, we have compiled a general summary from the records of the students at Human Resources School. This information represents a variety of findings, since each student has his own physician and may have attended different hospitals or rehabilitation centers.

Therefore, two important points must be noted. One is that each child is different, and so is the severity of his disability. The other is that medical procedures and recommendations are constantly advancing and changing, and these findings represent only a summary of the past.

Hemophilia – Hereditary disorder transmitted by females but usually affecting only males. An abnormality in blood coagulation resulting in prolonged coagulation time and lowered prothrombin (clotting factor II) consumption.

SYMPTOMS:

Hemorrhage occurring either spontaneously or after trauma (injury)

Joint swelling

Ecchymotic areas of skin (discolored areas where blood has escaped into the tissue)

HOSPITALIZATIONS AND TREATMENTS:

Blood transfusions

Local hemostatis (arresting of escaping blood by means of compression or tying off blood vessels with ligature)

Administration of antihemophiliac globulin and albumin (plasma proteins).

SPECIAL PROBLEMS NOTED AND RECOMMENDATIONS MADE BY DOCTORS:

Avoidance of any trauma; precautions as far as activities are concerned.

Swimming only after consultation with physician and swimming instructor.

Physical Therapy (ROM) in some cases, but prohibited in others because of resulting hemoarthrosis.

MENTAL HEALTH ACTIVITIES FOR ELEMENTARY STUDENTS

These mental health activities were followed at Human Resources School during the course of the Health Education Project. The curriculum activities incorporated into the mental health modules for K-12 were chosen after a reevaluation of these activities.

A. Meeting More Friends – Parents and School Provided Opportunities to Meet Friends:

1. Parents' meetings encouraged parents to provide a home environment for friendship to grow by inviting other children to their house for social activities, and to take their children to out-of-school social activities.
2. The school provided activities like the science fair to which students from other schools were invited.
3. The school afforded opportunities to meet as many school friends as possible by having flexible intergrouping for learning among 55 intermediate students in a large open classroom.
4. Class projects on making and being a friend have included role-playing, letter writing, learning the social graces through practical experiences in class parties, discussions about our students' feelings that they must "prove" themselves or compete for the friendship of non-disabled peers.

B. Identification with Appropriate Sex:

1. Disabled boys are most often cared for, bathed, and toileted by their mothers long after the age at which most boys have privacy and independence in these daily activities. Therefore a number of school activities were designed to encourage the fathers to take an active role in their children's lives. Fathers and/or male relatives and friends were invited and included in the following:

   Holiday programs and performances presented by the children

   Saturday participation in the infant and pre-school programs

   Family picnics on the campus of school grounds

   Family swim and recreation days

   Open school night

   Regular PTA activities this year: dance, fun auction, spaghetti supper, wine-tasting party, informative meetings on: curriculum, psychology, mental health, college and vocational preparation, and providing for the disabled child after parents' demise.

C. Development of Positive Self-Concept:

1. Center-wide cooperation to develop positive self-concept in all the students by having:

   (a) an approving milieu;

   (b) opportunities to excel: **Academically** – elementary health-science fair, Junior Red Cross essay and poetry contests; **In Sports** – Field day, basketball team, track and field events for handicapped; **Shows** – for Board of Governors, parents, and distinguished visitors;

   (c) experiences in independence – class trips to stores, U.N., major league baseball games, the circus in Madison Square Garden, the Bronx Zoo, a Pumpkin Farm, Santa Claus.

D. Learning to Communicate:

Activities which promoted competence were:

1. Original stage production
2. Puppet shows
3. Making audio cassettes to accompany exhibits or film strips
4. Telephone conversation practice
5. Letter writing to friends who move away, to classmates in the hospital, thank-you notes to guest performers or to hosts of some trips
6. Rap sessions which guided students to the conclusion that friendship means relaxing and being yourself and being interested in the other person.

E. Developing Peer Group Relationships through Inter-School Project with Non-disabled Students

1. During pre-adolescence, when peer-group identification takes on such great importance, the physically disabled child experiences:

   (a) the need for opportunities to meet more friends and then to be able to "get together" with them frequently.

   (b) a desire to show non-disabled peers that he can compete and win in some areas

   (c) worries about being rejected or avoided by non-disabled peers who think a disability makes a person "different"

   (d) lack of the social experience of interacting with other children as an equal, and so needs practice in communicating about his interests, opinions and ideas. To do this he needs to find a common ground of interest with others his age.

2. A peer-to-peer pilot program with a local elementary school provided the opportunity for able and disabled to work together on activities which both can do:

   Participation in safety health education activities developed the previous year

   Cooking together

   Library research projects

   Swimming

3. Rap sessions were held with a psychologist and teacher about feelings related to the peer-to-peer project. Discussions brought out feelings about the need to compete, and, under the guidance of the psychologist, observations by the disabled students that the best communication with non-disabled came at lunch or in talking over their activities or comparing opinions on big league sports or TV programs, not during competitive times.

4. Pre- and post-project meetings were held for the parents, the last meeting being a barbecue and reception for all the parents and children involved in the project. Conclusions showed that Human Resources School students did not show much change in attitudes toward the disabled because they had already scored high in positive attitudes and expectations. The non-disabled students did show positive changes in attitudes toward the disabled.

F. Understanding Human Growth and Development and Human Reproduction:

1. The School Nurse-Teacher, the Science Teacher, and the Classroom Teachers have worked together to prepare lessons which impart all the basic information about:

   The body systems and their functions
   Correct terminology for the parts of the body
   Conception and development of the baby
   Birth of the baby
   Physical changes during pre-puberty
   Changes in feelings
   Personality development
   Masculine and feminine roles
   Aspects of maturation

MENTAL HEALTH ACTIVITIES FOR SECONDARY STUDENTS

Team Teaching of Relevant Topics – additional instructional time for mental health was added to the program for all students on the secondary level. A team of experts – including the school nurse-teacher, the physician, the psychologist, the guidance counselor, and the health teacher – worked with the students as individuals and in groups on mutually chosen goals:

I. **Personality Development –**

A. Development of a Positive Self-Concept:

1. Discussions of students' abilities and assets led students to assess their previous successes in school and to plan for opportunities for wider success experiences. These include methods of coping with the activities of daily living and the establishment of wider social contacts.

2. The school health team worked with parents to broaden the students' success experiences in traveling to stores, churches, museums, libraries and recreation areas outside of the home or school.

3. A number of experiences were added throughout the school and the center with the long-range aim of improving the students' *self-concept* and *independence:*

   Wheelchair basketball team

   Cheerleading squad

   Pep rallies

   Participation in Wheelchair Olympics

   Student-faculty basketball and volleyball games

   Musical and dramatic play presentations

   Class trips to the State Capital to meet legislators

   Trip to Philadelphia to Independence Hall, etc. (each trip gives students an opportunity to spend several nights in motels, eat in restaurants, and cope with activities of daily living)

   Recreational trips to Washington

   Other Trips: fishing, museums, major league baseball games, and cook-outs, Long Island Science Congress participation.

   The school also made arrangements to invite non-disabled students to our school functions and to create opportunities for our students to be invited to school functions at schools for non-disabled students.

4. As part of our concerted effort to develop positive self-concept: Hair stylists spent a day at the school giving a free hair styling to all boys and girls who wanted one, and two beauty consultants from Glamour Magazine gave lectures, demonstrations, and individual consultations on skin care and make-up to all students.

5. A special bibliography of biographies of physically disabled people was developed by our students. A selection of these books was read and assessed by our disabled students.

6. Peer-to-Peer interpersonal relationships were developed between the disabled students at Human Resources School and non-disabled students in other junior and senior high schools through exchange-students days.

7. A half-day workshop and tour of the school was conducted by the seniors of Human Resources School for a group of Future Teachers of America from another local high school.

B. Development of Emotional Independence:

1. Students were given the opportunities and the responsibility for their own physical care, mobility and school work. Class time was spent in helping them understand why this was important for them.

C. Realistic Goal-Planning

1. An exploration of interests and opportunities was conducted with the help of the guidance counselor during the elementary and junior-high grades.

2. In senior high grades, students were helped to confront their disabilities realistically with the help of the guidance counselor, parents, and the OVR counselor.

3. Then the student was involved in outlining his own plans for the future.

D. Reinforcement of Feelings of Control of the Environment and Overcoming Frustrations:

1. Students have studied and applied methods of problem-solving and of decision-making.

2. Students invited as guest speakers successful alumni and other adults who are disabled, as well as professionals who are knowledgeable about disability. The information and advice shared in this program reinforced feelings that frustrations or problems can often be overcome through one's own efforts.

E. Knowledge of Alternatives in Dealing with Interpersonal Relationships:

1. Students have practiced and shared their experiences in making new friends.

2. They explored more constructive ways of getting along with parents, school mates and teachers.

F. Desire to Contribute their Abilities and Talents to the Family and to the Community:

1. Students learned to take the initiative in meeting non-disabled people.

2. They practiced answering questions about disability in a factual way.

3. They decided to "educate" the non-disabled about the abilities of the disabled through demonstration and explanation.

4. Many became involved in volunteer help in the school, and/or paid work at Abilities, Inc.

5. Through the junior and senior high basketball teams they traveled widely to demonstrate their prowess in athletics and in cheering.

6. The after-school recreation program added a "coffee house" program to which Human Resources School students invited all non-disabled students contacted through the various programs.

II. **Sexuality –**

A. Dealing with Physical and Emotional Changes in Adolescence:

1. Because some students are relatively helpless and/or incontinent, and require physical care, their parents tend to continue regarding them as children and do not recognize that they are maturing sexually. Therefore they needed more opportunities to explore their feelings.

2. Discussions about the feelings, problems, and social behavior of the average teen-ager gave insight to those disabled teen-agers whose experiences and contacts with non-disabled adolescents have been limited.

3. Enlarging their contacts with able-bodied teen-agers was continued in the peer-to-peer student exchange days with local junior and senior high schools.

4. More than the average amount of time was spent on lessons reviewing the physiology of adolescent development. This was necessary because some of our students had missed the instruction in previous years due to extended hospital stays. Others had been on homebound instruction. Many are "protected" by their families and tend to be naive or immature socially.

B. Coping with Special Problems of the Physically Disabled in Socializing with the Opposite Sex:

1. Basically the problems involve:

Logistics – managing the physical details of transportation, accessibility, etc.

Attitudes – of non-disabled toward disabled, disabled toward non-disabled, disabled toward other disabled, and disabled toward themselves.

2. Students worked on trying to cope with these problems of logistics and attitudes in:

Meeting members of the opposite sex – Because of the difficulties of transporting them, it is sometimes impossible for many of our physically disabled students to participate in commonly accepted activities whose function is to help young people meet other young adults:

local school athletic events
community or church dances or social events
activities in playgrounds, parks, or teen centers
belonging to local youth groups
visiting at a friend's house

The activities for self-concept enabled them to widen their circle of friends in and outside of school.

Dating – pros and cons of dating a non-disabled person. Pros and cons of dating another disabled person. Debates heightened awareness of their own attitudes.

C. Consideration of Problems of Sexual and Reproductive Ability:

1. Through individual counseling with the school physician, nurse, and psychologist, the older students considered the answers to the following questions:

Can I marry?
Can I have children?
Is my disability hereditary?

In addition, students received the information that there are centers where they can obtain such information when they are ready for it.

2. Genetic Counseling – through individual counseling with the school physician, nurse and psychologist, the older students have considered the following questions:

What is genetic counseling?
Is genetic counseling advisable for me?
Where is it available?

III. Family Life Education –

A. Child Care Experiences –

Senior boys and girls volunteered their services in both our infant program and pre-school classes for disabled children. Through the coordination of the teachers of child development and the pre-kindergarten and kindergarten teachers, seniors spent three periods a week in Human Resources' pre-school classes learning to help the younger children with their physical and learning needs, and giving the youngsters a sense of identification with young adults. They learned about the needs of young children and about their own ability to fulfill those needs if they have a family.

Beneficial Effects of Family Life Education and Child Development Experiences –

1. The opportunity to work with physically disabled pre-school children taught our seniors certain basic understandings about caring for disabled children, such as:

- the importance of movement to the child's physical growth and development
- the importance of play to induce the children to move
- that providing encouragement for communication can help children to develop language skills
- enriched opportunities can overcome experience deprivation in early years

2. The program benefited the young children in two ways:

It improved the self-concept of the little children because a senior student cared about them and played with them.

It improved their own expectations for the future when they saw the disabled seniors helping them and the teacher, and talking about their own independence.

3. The program benefited the seniors in three ways:

It improved the seniors' own self-image because the young children

looked up to and admired them, and it gave them an opportunity to be of service to others.

It gave the seniors more realistic expectations about their own abilities to care for a disabled (or able-bodied) child.

By participating in the infant program, the seniors had an opportunity to observe how mothers can care for and enjoy their disabled babies.

B. Preparing for Responsible Independence

1. Examples of simulation workshop activities which were held to help our students to develop realistic expectations:

   Make a plan to move to an apartment and be responsible for yourself.

   Investigate the costs of living on your own. Make a budget. List sources of income and probable expenses such as rent, utilities, food, clothing, etc. List methods of managing your washing, ironing, cooking, cleaning, shopping.

   Plan a wedding and reception. By phone and by car investigate the cost and problems of obtaining an accessible place, planning the menu, hiring musicians, caterers, photographer. Find out about the civil or religious arrangements necessary. Find out about blood tests required by law.

   Plan a party – invite the guests, plan the preparation of the refreshments, plan the decorations, make a budget of all costs.

   Prepare and act out a job interview.

Decisions on teaching about disabilities:

The dichotomy between the right to know and the right not to know has caused serious thought on decisions made by the health team.

We started with the premise that students have a right to know all about their disability. Since the information is contained mostly in medical journals or texts written in very technical language, there is a barrier to individualized research done by students. Pamphlets put out by related organizations, although written in more easily understandable language, often place emphasis on the disheartening, deteriorative or terminal aspects of the disability.

Information in understandable, yet objectively factual terms would have to be given to the students by the members of the health team either verbally, or by using and explaining selected audio-visual aids like film-loops, transparencies, or filmstrips, or by teacher-made devices or materials.

The decision to actively promote research by and share information with a disabled child had to be an individual one for each student. All children were given a summary of basic information. But the quantity and depth of additional information and advice was dependent on factors such as individual maturity, emotional stability, interest and obvious wish to know.

Progressive terminal diseases like Muscular Dystrophy present the most difficult decisions. There is sometimes a question about whether the burden of knowing that death is inexorably approaching within a few years may cause depression which prevents the young person from enjoying the years which he has. Some parents, particularly those of students having Duchenne Muscular Dystrophy, do not wish their children to know that their future is progressively hopeless. Adults dealing with terminally ill young people find it almost impossible to indicate that they know the future is death.

We have found that the older students who are already aware of the usual inevitable outcome prefer to hear and talk about the progress made in scientific research and express great hope that a cure will be found before they die.

Diseases in which the condition in many older students is improved, such as in osteogenesis imperfecta and dysautonomia, are sources of great encouragement to the younger children and to their parents.

In some disabilities, like those caused by traumatic injuries, knowledge and acceptance is necessary for the establishment of real motivation for independence in the activities of daily living and learning.

In each case where a decision was made to impart information in depth, an accurate explanation of the disability and a discussion of the future was given by the school physician who has an excellent rapport with the students in addition to many years' experience in advising physically disabled children.

After working with the students and their families and trying to decide what information to give the children about their disabilities a major conclusion has been that hope is a beneficial, realistic aspect of the education of the disabled. The advice given to teachers and parents is this: Don't take away hope. Hope gives a person the will to try and the courage to help himself, to become more independent, to plan for tomorrow. The effort exerted when a person tries to help himself is physically beneficial to his circulation, breathing, bone growth, and appetite. The mental stimulation involved in planning, learning, and working for tomorrow is psychologically beneficial. It helps him to put pain or discomfort into perspective, not to concentrate exclusively on it. He now has other worthwhile, interesting thoughts to occupy his mind.

There are some realistic reasons for encouraging hope. Antibiotics enable people to overcome infections and respiratory complications that used to cause death. Researchers are getting closer to cures for many serious illnesses. They are also finding ways to avoid or overcome birth defects. So, in fact, there is hope for a better future for most disabled young people.

So, in educating young people about their disabilities it is important to teach the hopeful aspects. Emphasizing the painful or terminal outlook attached to some diseases does not encourage people to live today to the fullest.

Most of the topics covered in the New York State Curriculum in Mental Health and Family Life Education are appropriate in some way for physically disabled students because these children with "normal" intellectual capacity need all the knowledge and guidance appropriate to other young people of their age. These topics and activities have been tried and accepted as appropriate throughout New York State.

However, with some topics the teacher needs some special understanding of the relationship of the topic to the needs of the disability.

Some topics need to be taught more thoroughly at a higher grade level or a later age because children have missed school during hospital stays or because of the naïveté of children resulting from excessively sheltering attitudes of adults around them and lack of contact with non-disabled peers.

Some special topics needed to be added because of the necessity of coping with disability-related problems.

Because of the limitation of printing costs, those topics which are appropriate and do not need any special understanding on the part of either the teacher or student have been merely listed in the appendix. The teacher may refer to the New York State Health Education Curriculum available from ERIC (K-3 on Microfiche #ED070994, 4-6 on Microfiche #ED072337, 7-9 on Microfiche #ED037737) and 10-12 not yet published by N.Y. State, or any standard textbook for appropriate information on these topics.

Those topics which require a special understanding of the relationship of the topic to the needs of the disability have been explained on the teacher background page.

Those which are special disability-related topics have been given fuller treatment.

All of the concepts, activities, and background information are those recommended by the health project committee as a result of the health curriculum activities conducted in our school for three years.

EVALUATION

Ongoing evaluation and revision was done on each module.

The units included in each module are those evaluated by the teachers, students, and parents involved and given a rating of good (3), very good (4), or excellent (5), on the following items:

Relevance in fulfilling assessed needs

Helpfulness in improving students' health knowledge

Productiveness in establishing more positive attitudes

Motivation in developing good health habits

Evaluation of student learning was done by the students themselves by performance of the student self-evaluation activities. These activities gave each student the opportunity to demonstrate what he had learned in an enjoyable, non-competitive way.

The self-evaluation activities included in column three on each page are the ones rated good (3), very good (4), or excellent (5) by those who worked with them.

In addition, a student evaluation of classes in mental health, family life and sex education which used these activities indicates that 85% felt that the class was worthwhile, 80% felt that the presentation was appropriately frank, most of their questions had been answered, and that the information was easy to understand. 75% felt that the class helped them to gain new insights into human relationships. (See Table 1)

At the beginning of the project 50% of the students could name and describe their disability. At the end 95% could.

Table 1.

STUDENT EVALUATION OF THE MENTAL HEALTH, SEXUALITY AND FAMILY LIFE EDUCTION PORTION OF THE PROJECT

	Strongly Agree 5	Agree 4	Un-decided 3	Dis-agree 2	Strongly Disagree 1
1. The family life and sex education class was worthwhile	60%	25%	5%	10%	0%
2. I thought the whole presentation was appropriately frank	40%	40%	10%	10%	0%
3. Most of my questions have been answered	40%	40%	10%	10%	0%
4. The information was easy to understand	35%	45%	5%	5%	5%
5. The class helped me to gain new insights into human relationships	40%	35%	5%	10%	10%

Name and describe your disability:	At beginning project 50% could	At end of project 95% could
What areas were most interesting:	Child development experiences; Working with pre-schoolers	

What areas were most helpful:	Dating, friendship, guest speakers, physical maturation
List problems related to personality development, sexuality, and family life education that you have encountered because of your specific physical disability:	Dependency on other people; Lack of friends outside of school; Unable to meet or go on dates; Can't go wherever I want
In what ways has this course enabled you to approach your problems in a more positive way:	Most felt that their increased knowledge, and insights resulting from the discussions, helped them to cope in a more mature way.

Typical Responses

"It's given me a brighter outlook on my life problems. I can face them better and handle them in a more mature way."

"I can make the best of it."

"To realize that you can't always get what you want and try to cope with what you have."

"I thought my development was abnormal. It made me feel better. I learned that I still have time to develop."

"It made me more open."

What topics should be discussed if the course is repeated:

General Problems

"Having babies."

"Sexual contact."

"Being teased and made fun of."

Problems Related to Your Specific Disability

"Whether the disability would hamper sexuality."

"Dependency on other people."

"Talk about our disability outloud – let the other kids know just what is wrong with you so that we can understand each other better."

"Progress report on finding cures for our disabilities."

"Meeting new friends."

"Get together with parents and staff and other kids to talk about our feelings."

"If we can have children."

Acceptance of Disability Scale

The Acceptance of Disability Scale by Donald Linkowski was used as a measure of the students' psychological adjustment to their physical disabilities. Observations by the entire project committee agreed with the hypothesis of the AD Scale's author, that greater acceptance of disability does not correlate with severity of the disability, but seems to be a quality of how the person perceives his own limitations.

The test gives 6 levels of agreement or disagreement with 50 statements about the effect of a disability on a person's future, social life, happiness, etc. A possible perfect score would be 300. The students took the test at the beginning and end of the third year of the project.

The average score at the beginning was 239.3 and at the end of the year 241.3. Although the impovement is not significant, the fairly high levels at the beginning of the third year indicate a better than average adjustment to disability among the students at Human Resources School. An already high score was difficult to improve upon. It is regretted that this scale was not given at the beginning of the first year since the project staff feels that more significant improvement occurred during the second year. Results backed up the claim that severity of disability did not seem to correlate with higher or lower scores.

Community Cooperation

The health project has resulted in greater cooperation between the school and community. Examples include:

Tours, workshops, and seminars with educational, medical, mental health and professional groups.

Cooperative projects with C.W. Post College, Hofstra University, the Council for Exceptional Children, North Shore University Hospital, and Adelphi University.

Intervisitation of Human Resources School with local high schools, junior high schools, and elementary schools.

Student Acquisition of Both General and Specialized Health Knowledge and Behaviors

The two most important accomplishments of the health project were:

1. The physically disabled students became aware of their commonality with "normal" students in needing to adopt daily and regular procedures for maintaining and preserving emotional well-being.

   Their improved awareness of health knowledge and adoption of better health behaviors were demonstrated by improved scores on both the AAHPER Cooperative Health Education Test and the Health Behavior Inventory.

2. The physically disabled students gained specialized knowledge and behaviors such as these:

   a. became aware of the special procedures which could minimize health problems related to their disabilities

   b. learned about sources of help for the disabled

   c. developed ability to share information about their disability objectively

   d. increased their acceptance of the responsibility for their own health and welfare

They demonstrated these gains by developing the learning concepts, activities, and self-evaluations which they wrote up for these modules. They also showed these gains by improved responses on questionnaires, class tests, and class discussions and projects.

Mental Health & Family Life Education Module

Grades K - 3

Special Topics in This Module	Objectives
I. The Family As a Social Unit	
A. Children's Role	Understand the children's role in the family.
B. Parent's Role	Learn what your father and mother do for you.
II. Understanding the Life Cycle	
A. Male and Female Gender	Understand the meaning of male and female gender.
B. Meaning of Reproduction	Learn the meaning of reproduction.
C. Parents' and Child's Role in Caring for Babies	Appreciate each family member's help in the care of a baby.
III. Human Growth and Development	
A. Physical Development and Body Image	Understand that children have likenesses and differences in appearance and growth.
B. Social Development and Friendship	Learn ways to act like a friend.

BACKGROUND INFORMATION K–3

I. The Family As a Social Unit

A. Children's Role – 1

General – Be sure to include wedding and family pictures of disabled people. Children should be helped to understand that both disabled children and disabled adults can be part of happy families and that a physical disability does not change their relationships.

Children's Role – 2

General – Since the physically disabled child will become quite conscious of the difference between his siblings and himself in physical appearance or physical ability it is helpful to him to point out that other children also differ in a variety of ways and that each child is unique and special in his own way.

Disabled persons' attitudes toward themselves are much more important than the nature or extent of their disabilities. Disabled persons who accept themselves and their disabilities tend to be relatively well adjusted, highly motivated, and hard workers, regardless of the extent of their physical disabilities. They are the ones who emphasize ability, not disability.

Children's Role – 3

General – It is important that disabled children acquire at an early age a sense of responsibility to other family members, rather than merely developing habits of being waited on, which, in the long run, will deprive them of independence. Because of their need for special attention, they may have difficulty learning to accept responsibility.

1. **Dysautonomia** – Because of their need for attention, these children may have difficulty learning to accept responsibility. Being allowed to accept responsibility in the family group is a first step in accelerating social maturation which tends to be slower in dysautonomics.

2. **Spina Bifida** – Because separations from the family have probably been necessitated by hospital stays, it is doubly important for these children to develop a sense of responsibility toward their share in family life. Parents should be encouraged to show a consistent expectation that their child will perform some service for the family on a regular basis, even if the training takes parental help in the beginning.

3. **Muscular Dystrophy** – Primary age children may be falling with increasing frequency. However, there are a number of helpful tasks which they can perform without climbing stairs or being exposed to falls against sharp corners. A feeling of being useful and needed, which can be developed at this time, could help their self-image at a very difficult period in their lives.

4. **Arthrogryposis** – The inflexibility of their limbs makes these children physically dependent and sometimes demanding. A special effort should be made by parents to encourage them to be contributing members of their family in some way. They may be able to give in a verbal sense, by story-telling or singing, or by being the listener. As they get older they can help others with homework or read to the family.

5. **Congenital Amputees** – The family should encourage an independent role by expecting the child to help the family in whatever way he is able. Helping him to find ways of using his prosthesis in the tasks he performs will help him physically while also developing his self-image.

6. **Osteogenesis Imperfecta** – These children should find something they can do for the family which does not require physical strength. Functional movement of their muscles is beneficial when they are not in a cast. Since the condition improves after puberty, and they have a normal life expectancy, they need to learn to develop independence and accept responsibility. Giving them something they can do might also cut down on "chatterbox" syndrome.

7. **Achondroplasia** – Regular family responsibilities can help the child to realize his place in the family and to feel secure in spite of his small stature. Parental treatment and expectations should be according to his age and not according to his size.

8. **Congenital Cardiac Conditions** – In spite of physical limitations, a child with a cardiac condition can accept some suitable responsibility at home. If nothing is expected of him the child may feel "different" or "useless," so a cooperative duty that is not physically taxing should help his self-image. Most children with a cardiac condition will limit themselves in any physical activity.

9. **Hemophilia** – Parents' guilt feelings sometimes allow their children to avoid chores. In addition, from fear of making demands on the child they overprotect them. These children are capable of accepting responsibility and can develop self-discipline through cooperating in family duties.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
I. The Family as a Social Unit		
A. Children's Role		
Objective: Understand the children's role in the family.		
1. Your family includes your mother, father, sisters, brothers, and other relatives.	1. Bring wedding pictures and family albums to class. Point out the bride, groom, husband, and wife.	1. Explain the meanings of these words to your teacher.
	2. In your family album show the class your baby pictures and pictures of your parents with you when you were a baby.	2. With your teacher have a class discussion on "Why People Marry" and "Why People have Children."
	3. Make a bulletin board of family photographs.	3. By using the bulletin board, introduce the class to your most important relatives.
2. Children in the same family may vary in physical traits as well as abilities, interests and maturity.	1. Draw a picture of each child in your family. Under each drawing list the qualities that make that child special.	1. Discuss why each member of your family is loved by the others.
3. All children can help their family.	1. Using your dramatic ability, demonstrate exactly how you help your family by doing some chores.	

BACKGROUND INFORMATION K–3

B. Parents' Role

Parents of a disabled child often have a difficult and important role in the rearing of their child.

General – Disabled boys need opportunities to relate to and identify with adult males. They are most often cared for, bathed, and toileted by their mothers long after the age at which most boys have privacy and independence in these daily activities. They may not have many occasions on which to relate to a father figure. The school may encourage the fathers or a male friend or relative to take an active role in the children's lives by providing activities in which they can participate. Parent education for the father is a very important adjunct to the program.

Studies suggest that some experience deprivation among cerebral-palsied children can be traced to the disengagement of fathers from involvement at home and in school programs.

Sensory (and probably experiential) deprivation plays a part in infant growth and has pervasive ramifications for a child in the intellectual, social, and affective domains. For this reason it is important that both parents of a disabled child be instructed and motivated to help him by supplying an abundance of stimulating opportunities to move, speak, and socialize.

A disability in their child may add problems to a marriage if the couple has had the child for one of the following reasons: to satisfy grandparents, to prove their potency or fertility, or to hold the marriage together. If their child is disabled, none of these functions is fulfilled.

Parents need help in a number of ways – Physicians and health professionals must be available to them to answer their questions. They usually ask – Why did it happen? Will it occur again?

Parents' meetings and discussion could be based on *Even Love is Not Enough, Children with Handicaps,* Parents Magazine's Special Education Sound and Color Filmstrips: "Physical Disabilities" – contains five color filmstrips, 12 LP records or three cassettes, discussion guide, and five audio script booklets. Filmstrips on Physical Disabilities cover these topics: (1) Three Different Kinds, (2) Special Problems, (3) What Can We Do? (4) Diagnosis and Treatment, and (5) Support Services.

The Series consists of four separate filmstrip sets: Behavioral and Emotional Disabilities, Physical Disabilities, Intellectual Disabilities, and Educational and Language Disabilities.

Produced by Parents' Magazine Film, Inc.

1. **Dysautonomia** – Because of a lack of ability to adjust to change, the child with dysautonomia needs a much more stable and predictable environment. A parent should plan a daily schedule of feeding, bathing, play, and sleep for the infant and make a special effort to follow it systematically. As the child gets older, schedules should be actually written down so that he can feel that his external environment is predictable and secure. For his emotional security, frequent parental concessions may be more "frustrating" than the setting of definite limits for behavior and routines for the activities of daily living.

2. **Spina Bifida** – There is early awareness at birth by parents because they have to deal with the problems directly. This disability cannot be denied as some others are. There is quite a bit of maternal mourning because of early detection. Often the mother doesn't socialize or encourage her disabled child to interact with other children, so there is anger in the mother toward the child because of her isolation and there is social deprivation for the child. Because so much of infancy is motor development this makes mothers very conscious of differences in their babies. Acceptance of their disabled child may come gradually or never totally in many cases.

6. **Osteogenesis Imperfecta** – In severe cases there is early awareness of disability. Multiple fractures often occur during birth. There is depression in parents. Encouragement and instruction of the parents is needed in treating the child normally because he will improve and should learn how to be independent. He needs to learn to mature as normally as possible and to be an independent person. Parents need encouragement to allow the child opportunities to grow to the extent that he can, and let him try to do things for himself. They can protect him from trauma and guide him but they can't stop all fractures anyway.

9. **Hemophilia** – Parental problems with the hemophiliac child include: worry about injury, anguish of watching pain, a sense of futility, worry about cost, "guilt" feelings in the mother, father blaming the mother. Parents may use denial or may be strong during bleeding episode and then have reactions

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
B. Parents' Role		
Parents have an important role in the life of a child.		
Objective: Learn what your father and mother do for you.		
1. Father's Role		
1. Students can take steps to know their fathers better.	1. Plan a series of programs, for the year to which you will invite your father, brother, or uncle. Possible activities: Holiday programs or plays, Family picnic for the class, Family recreation or field day, Open school night, "Father's Day," Evening meetings.	1. Make a list of topics which your father is interested in (for example – a sport, daily news events, a hobby, "the old days" when he went to school). Find out as much as you can about the topic. Then ask him all about the topic and tell him what you know. Make a booklet of all the things you learned from him and give it to him for Father's Day.
2. Mother's Role		
1. Students can find ways to understand their mothers better.	1. Invite your mother to join a "class mothers" group who could form a telephone chain to tell others about school closings, special events, etc.	
	2. Plan a "mother's day" program in which you each act out three important things your mother does for you.	2. Invite your mother to the program and plan to serve her refreshments and treat her as an honored guest.

of depression or irritability. Hemophiliacs who have good relations with father are more successful and happier regardless of severity of bleeding episodes. Siblings may be very attached or may be jealous. Feelings of helplessness in parents may be turned into anger and criticism of mate. This may be overcome by learning all they can about the medical, physiological, and psychological aspects of the disease. Helping other parents of hemophiliacs by sharing experiences helps them by reducing the sense of isolation.

If parents realize that some bleeding episodes will occur regardless of the most stringent precautions, they can stop blaming themselves for every episode and use reasonable precautions. If possible, it is better for the hemophiliac to conclude through personal experience that a particular activity is dangerous rather than to have parental authority establish a restriction.

Parents must agree on their expectations of the child's behavior and on their methods of discipline because the child who becomes "overprotected" may become manipulative and demanding.

I. Understanding the Life Cycle

A. Male and Female Gender

General – Disabled children need to understand stages of normal growth and behaviors, since they may not have the usual opportunity to observe and associate with many "normal" children of various ages.

B. Meaning of Reproduction

General – Because physically disabled children are often very "protected" by their families and because they often do not have the opportunity to visit pet shops and zoos, or perhaps observe pregnant women in stores, streets, or friends' homes, they need clear and thorough instruction about the meaning and normalcy of reproduction.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
II. Understanding The Life Cycle		
A. Male and Female Gender.		
Objective: Understand the meaning of male and female gender.		
1. Girls grow into women and boys grow into men.	1. Bring in some of your mother's and father's clothes to dress up in and "play house."	1. On the board make a list of all the students' brothers and sisters in age order. Then, starting with the youngest brother or sister, have each student tell how that brother or sister acts at each age (baby, elementary school, boy or girl – pre-teen, teen-agers, grown-up).
B. Meaning of Reproduction		
Objective: Learn the meaning of reproduction.		
1. All living things grow from other living things like themselves.	1. In class groups grow seeds, raise animals and fish and observe young being born. Visit a baby animal zoo or baby animal farm.	1. Match pictures of adult and baby birds, animals, and humans.
2. Life begins in an egg.	1. Incubate fertilized chick eggs until they hatch. Each day examine one egg, break it open, and observe the progress in development.	1. Each day make a drawing and a chart showing how much more the chick has developed. Display these for parents and other guests and explain them for the visitors.
3. An egg from the mother is fertilized by a sperm from the father and grows into a baby.	1. On a calendar, count the *40* weeks which a human baby grows inside its mother.	1. On a worksheet, follow the teacher's drawing on an overhead projector of diagrams of female and male reproductive organs. Draw diagrams of egg and sperm.
4. The baby develops inside its mother until it is ready to be born.	1. Show pictures or plaster models of stages of baby's growth inside the mother.	

C. Parents' and Child's Role in Caring for Babies

Disabled children need to realize that they have an opportunity and an obligation to help the baby. The opportunity to show maturity and independence may not have presented itself before. They can be helped to view their cooperation as important and also to appreciate all that was done for them.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
C. Parents' and Child's Role in Caring for Babies. **Objective:** Appreciate each family member's help in the care of a baby. 1. Families help babies to grow and develop by providing food, clothing, shelter, love, care, and help in learning how to walk, talk, and do things.	1. Ask your mother why mothers have babies in hospitals and then explain the reasons to the class. 2. Have a "Baby Day". Ask classmates with baby brothers or sisters to ask their mothers to bring the babies to school. 3. Ask the students to introduce their babies to the class. 4. Ask classmates to find resemblances between baby and student brother or sister.	1. Have a student or a pregnant mother tell about a baby shower and all the things necessary to prepare for the baby's coming. 2. Tell the class the things you like best and least about having a new baby in the family. 3. Tell what responsibilities you now have because of the new baby. 4. Make a scrap book, diary or photograph album showing you helping the baby or your parents.

III. Human Growth and Development

A. Physical Development and Body Image

General – Many studies see a direct relationship between the perception of the body-image and a child's actions.

In school achievement, even average or superior cognitive abilities may not show their potential because of an abstraction problem traceable to poor or immature body image.

Those who did not achieve in reading and related learning areas, were those whose body-image concepts were immature or almost non-existent. A close relationship between the two types of learning is suggested.

Pre-school and early elementary and home activities, should be geared to the earlier development of positive and accurate notions of the body-image and self-concept.

Through the use of a draw-a-person test developed by Machover, Wysocki (1965) found that physically disabled children can be differentiated from nondisabled children in terms of their higher levels of feelings of inferiority, anxiety, and aggression. Physical insults appearing in the figure drawings tended to correspond with the child's own disability. In drawing non-disabled persons, disabled children tend to be realistic about the differences that exist between themselves and others.

Disabled students especially need to understand the functioning of their body systems since they often overhear physicians and parents discussing their physical problems. This basic information would also serve as a basis for a clear understanding of the relevant physiology of their disability when they are older.

1. **Dysautonomia** – Frail and small body structure may affect body image. Frequency of urination, which makes young children difficult to train, and bedwetting persistent longer, also complicates the development of a maturing body-image in children with dysautonomia.

2. **Spina Bifida** – An important aspect of body image for children who are incontinent is bowel and bladder control. A bowel and bladder control training program is vital to improving their body image.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
III. Human Growth and Development		
A. Physical Development and Body Image		
Objective: Understand that children have likenesses and differences in appearance and growth.		
1. Children's bodies are alike in many ways, but every child is individual in some ways too.	1. Outline the feet of a classmate on colored paper. Then cut out ten sets of "footprints" and put them on the floor leading around the room.	1. Take turns following in your classmate's footprints.
	2. Pour plaster of paris into an aluminum pie plate. When it is partly dry, make a handprint. When it dries, paint your handprint gold	2. Give your golden handprints to your mother for a present.
	3. Take photographs of two other classmates.	3. Tack all the photographs on a bulletin board and under each one list 5 things you know that your classmate can do well.
	4. Lie down on a big sheet of brown paper. Have a classmate or teacher draw an outline and draw in and color your face, hair, clothes, etc.	4. Tack up your drawing of yourself with those of your classmates and invite another class to come and match the drawings with the correct class member.
	5. Draw a portrait of a classmate.	5. Underneath it, write two things that you like about his appearance.

BACKGROUND INFORMATION K-3

3. Muscular Dystrophy – The severity of the abstraction difficulty seems to depend upon the quality of body image achieved by the time the MD symptoms are first perceived by the child as debilitating, i.e., the extent to which they prevent the child from experiencing an integrated, positive physical image of himself.

4. Arthrogryposis – Poor body image because of relative helplessness caused by immovable joints.

5. Congenital Amputee – Because of disfigurement this child is often rejected by peers. This could adversely influence the development of body-image and result in timidity or anti-social behavior. Teachers should encourage the use of available resources. If the child does not have an artificial limb, help parents find out about and use them. Most children usually have them, however. There are frustrations in changing appliances as they grow. There are often pressure pain, and discomfort as proper fit is constantly affected by growth. If children can learn to accept what they don't have they can develop a more positive body-image. Help them to handle questions and curiosity with a simple answer.

6. Osteogenesis Imperfecta – Several problems affect the body-image and self-concept of a child with O.I. When young there is timidity about being handled. Anxiety comes when they think they're going to be handled by someone who doesn't know their situation. They often have infantile behavior due to overprotection.

Isolation is caused by lack of a natural means of bringing the child into contact with young people of his own age. There is also chronic anxiety that the natural exuberance of peers might cause O.I. physical harm.

Pain and separation from the family while hospitalized after each fracture, and feelings of rejection when they cannot come to visit, may cause a negative image. There is no privacy at home or in the hospital for the child to care for his own body.

Still, these problems are easier to deal with than problems and frustrations imposed by others: chronic curiosity and staring. Activities which recognize ability while honestly facing the disability can help to desensitize the disabled child to the staring.

They feel they make a more impressive appearance sitting down than standing on short legs on crutches and having people tower over them.

7. Achondroplasia – Because of their size young children with achondroplasia are treated as dolls or babies. The reaction of the dwarf to widespread babying is: 1) behavioral infantilism, 2) reaction against babying, 3) denial, 4) social isolation, and 5) mascotism.

Help the child to realize his place in the family and to feel secure in his role in spite of his smallness in stature. As he grows older the role must change accordingly.

Fortunately, achondroplastic persons are often endowed with the personality traits of chronic cheerfulness, optimism and confidence. This can be encouraged by treating them with the dignity befitting their age.

8. Congenital Cardiac Conditions – Physical limitation that a damaged heart imposes may preclude many activities in which most of us routinely engaged as children. Some of these (e.g., skipping rope, playing sandlot baseball) further developed our physical capacities (and, incidentally, our self-confidence) and contributed to our strength and agility.

Students with congenital cardiac conditions miss these opportunities.

9. Hemophilia – If parents have helped establish a realistic, positive outlook he will be able to minimize the difference (in potential for bleeding) between him and his peers and he will recognize all the ways he is similar to his friends. Since his disability is not apparent unless his joints are affected, his body image may depend on the reactions of others. Education in school is preferable to homebound tutoring because stimulation to learn is given in school by peers. In addition, he needs their companionship.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
2. Each of the body systems has special functions: muscular skeletal respiratory circulatory digestive excretory nervous reproductive	1. Assign one system to each group. Let one representative lie on cardboard or plywood, on the floor while another draws an outline of his body. Cut out the body figures. Draw in the body system assigned to the group. Stand the "bodies" around the room and have each group explain their system to the rest of the class using correct terminology.	
3. Every child has his own pattern of growth and development.	1. Weigh and measure each child in the class every 3 months. Children who cannot stand may be transferred to a cot and measured with a tape measure. Children who cannot stand may be weighed on a platform scale. Note should be made telling whether the children were weighed with or without the braces.	1. Ask your school-nurse teacher what growth pattern to expect at your age. Keep your own record.

BACKGROUND INFORMATION K–3

B. Social Development and Friendship

General – One of the major problems in the social development of physically disabled children has been lack of opportunity to make friends. Isolation at home or in separate schools has prevented contact between them and their able-bodied contemporaries.

One answer to this problem is "mainstreaming". Another is joint programs between special and regular schools. Assembly programs, sports exhibitions, special movies, musical concerts, and so on would make good joint introductory activities.

Findings show the importance of providing favorable interactions with orthopedically handicapped children so that nonhandicapped children can develop a more positive and realistic perception of this special population. Traditionally, the education of children with special needs, occurs in facilities separated from the education of nonhandicapped children. As a result, nonhandicapped children often develop an inaccurate perception of handicapped persons which continues into adult life.

A study of the effects of mainstreaming on elementary school children's attitude toward orthopedically handicapped children suggests the following conclusions:

1. Nonhandicapped children's attitudes can be changed toward a more positive perception of orthopedically handicapped children as a result of an integrated school experience.

2. After integration the orthopedically handicapped children were perceived as less weak and less dependent, i.e., orthopedically handicapped children were perceived as more able to care for themselves than originally thought.

3. Increased interaction with orthopedically handicapped children resulted in the development of similar positive attitudes among elementary school boys and girls toward orthopedically handicapped children.

4. Attitudes toward orthopedically handicapped children varied with age or grade. Integration increased differences in attitudes between younger and older children. Older children viewed orthopedically handicapped children in more realistic ways.

Physically disabled children need to be encouraged to learn that they must participate equally in making friends with others. They need practice in taking the initiative in acting friendly. They also need a heightened awareness of their own social obligations to others, since they are often catered to and may come to accept the efforts of others to be friendly to them. They need to be assertive as well as responsive.

In their efforts to be "like other kids," physically disabled children may be more anxious to please or to prove themselves and thus more susceptible to peer pressure. In their efforts to gain acceptance they may respond to dares or resist the advice of their parents.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
B. Social Development and Friendship **Objective:** Learn ways to act like a friend. 1. Friendship means helping, sharing, enjoying and playing together.	1. List 5 ways in which you can show yourself to be a friend, try out each one this week and report on how you felt after doing the things you listed. 2. Use hand puppets to role-play a conflict between doing what your parents tell you to do and what your friends dare you to do.	1. Practice showing friendship by being interested in other boys and girls. Invite another class to a "get acquainted" party. Choose one guest and ask him or her all these things about himself. Listen carefully to him and remember his answers: What is your name? Where do you live? What do you like best about school? What do you like least about school? What is your favorite TV program? What is your favorite team? What is your favorite pastime or hobby? Do you have any brothers or sisters (and ages)? Then tell him the same things about yourself.

Mental Health & Family Life Education Module

Grades 4 - 6

Mental Health 4-6

Special Topics in This Module	Objectives
I. The Family as a Social Unit	Observe and appreciate how your family helps you.
II. Role Arrangements in Family Life	
A. Role Identity	Learn to identify with the physical and social roles of the parent of the same sex.
B. Human Reproduction	Understand the basic facts of human reproduction.
III. Personality	
A. Positive Attitude and Positive Self-Concept	Appreciate all the things you can do.
B. Improving Personality through Communication	Practice communicating with friends and strangers.
C. Experiencing Independence	Increase the number of things you can do.
D. "Modeling" – Learning from Older Disabled Students	Learn how an older disabled student succeeds in school.
IV. Growing Toward the Teen Years	
A. Individual Patterns of Physical, Social, and Emotional Development	Understand and accept the individuality of patterns of development.
B. Peer Relationships	Learn to develop peer relationships.

BACKGROUND INFORMATION 4-6

I. The Family as a Social Unit

General – Parents of a disabled child can benefit by the cooperative help of the school. The staff can help them to realize that they can and should encourage their child to meet friends and become more independent. Teachers should let parents know that discipline and the setting of limits are procedures which are beneficial to their disabled children. This would be a way to encourage their children to become responsible citizens from their earliest years. By assuming responsibility for their own actions, children also gain independence. The parent who has accepted and adjusted to his child's disability does not continue to suffer the mental torture of tragedy. He can and does find gratification in helping his child lead a purposeful life, and life begins to encompass not only suffering and despair, but also accomplishment and satisfaction.

Small-group parent meetings should also be used as a follow-up to encourage parents to provide a home environment for friendship to grow. Meetings should emphasize the importance of fostering responsibility and independence in their children.

Often disabled children share their siblings' friends. They see themselves competing with their siblings for the friendship of other children. They feel that their siblings take away their friends if they bring someone home.

They need guidance to examine the situation to see whether they are really acting like friends.

Family and siblings should make an effort to let the disabled child have the full attention of his friends when they come to the house. The family needs to be aware of the possible feelings of rivalry and help the disabled child and his siblings to plan and join activities together so that they are cooperating in a situation, instead of competing. They should also help the children to do things together in which they can be on an equal basis, like shopping, quiet games, etc.

1. **Dysautonomia** – The parents of the child with dysautonomia are very concerned about structuring the environment to meet the needs of their children. They are usually very willing to be involved in research.

If the child has not learned to control the vomiting reflex (some cannot once the cyclical vomiting has started) he can manipulate his parents who find it difficult to set limits and are vulnerable to overindulgence.

It may help parents to know that their children should become more capable in the activities of daily living as young adults. Parents can then be encouraged to be firm for the child's own good. They can also try to help their children meet and make friends and attend events where they can be with other children their own age.

2. **Spina Bifida** – Children are dependent upon mother for much of their personal care. Therefore, independence is hard to learn. Allowing these children to be independent persons is very important to their overall personality development. These children can be productive adults because they can learn to drive, attend further schooling, etc. If helped with their personal care management problems, they can be very well-adjusted adults (all things being equal).

3. **Muscular Dystrophy** – Parents can make a special effort to take a child of this age on outings, even though he may be increasingly wheelchair-bound. They can be helped to realize that life does not end when you are sitting in a wheelchair.

7. **Achondroplasia** – Parents are always looking for something to make their children grow and need help to accept child's size. By treating them according to their age and not their size, parents can encourage independence.

9. **Hemophilia** – Reasonable physical activity is a method of adjustment. Joints protected by well-developed muscles may be less prone to damage. Boys often voice dislike of bedrest and confinement to a wheelchair. Father can help by joining and supervising a variety of activities such as swimming, golf, bowling, tennis and controlled basketball.

Within the special limits imposed by the disease, parents should behave with very little difference from any other parents. Enduring misfortune may explain but cannot justify departure from common sense practice.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATION
I. The Family as a Social Unit **Objective:** Observe and appreciate how your family helps you.		
1. The family can take an active role in helping the disabled student to meet friends and to become independent.	1. Arrange to meet with the school psychologist, guidance counselor, school nurse-teacher, health education teacher, and your parents. The purpose of the meeting would be to help plan out-of-school social activities, and to inform the parents about how transportation could be arranged. Besides transportation, have some discussion about the accommodations for your social event and what you expect your parents' role to be.	1. List three out-of-school activities like to attend. Find out by telephone or the next event (or game, meeting, etc. place. 2. Make a contract with your paren *you* take responsibility for cooperatin arrangements if *they* cooperate on transpo 3. Learn and practice three rules of go for a party and then practice them at hom

	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
ow ple eet	1. Arrange to meet with the school psychologist, guidance counselor, school nurse-teacher, health education teacher, and your parents. The purpose of the meeting would be to help plan out-of-school social activities, and to inform the parents about how transportation could be arranged. Besides transportation, have some discussion about the accommodations for your social event and what you expect your parents' role to be.	1. List three out-of-school activities you would like to attend. Find out by telephone or letter when the next event (or game, meeting, etc.) will take place. 2. Make a contract with your parents in which *you* take responsibility for cooperating on time arrangements if *they* cooperate on transportation. 3. Learn and practice three rules of good manners for a party and then practice them at home.

BACKGROUND INFORMATION 4-6

II. Role Arrangements in Family Life

A. Role Identity

General – Maleness and femaleness refer to biological characteristics. Masculinity and femininity refer to patterns of behavior that are characteristic of males or of females in a particular culture. These patterns of behavior are not present at birth, but are learned through experiences one has in his family, his school and his community.

Because of lack of opportunity to participate in "feminine" activities with groups of other girls, disabled girls can benefit from instruction in how to dress and act in attractively feminine ways.

Boys are most often cared for by their mothers and lack the opportunity to observe and emulate their fathers. For a balanced viewpoint opportunities should be provided by the teacher to include fathers, uncles, older brothers, etc. in school and class functions. Teachers may also encourage boys to observe and communicate with the men in their family on topics related to school, social life, sports, etc.

Boys who are unable to participate in physically aggressive activities may be helped to understand that maleness or femaleness does not depend on ability to perform feats of strength – and that many activities, while culturally oriented toward men or women, do not have to be accepted as masculine or feminine activities.

1. **Dysautonomia** – Help boys whose growth is slow to identify as males. Tendency to small stature (slower growth pattern) might cause difficulty in identifying. Anxiety about body image. Can't feel sexual sensation on external level. (Male masturbation may be caused by lessened sensation of pleasure.) Girls often mature at a slower rate, thus feeling less feminine.

2. **Spina Bifida** – Males – poor body image. Males have great difficulty identifying as males because of their incontinence and the necessity of wearing urinary collecting devices, or as young boys, wearing of diapers past the normal age for diapers. Also the males do not have the normal sexual responses (the penis is flaccid). The girls usually have precocious development of their secondary sex characteristics. Probably responses are diminished to some extent. They need good instruction in veneral diseases and genetic counseling. Girls feel feminine because of their growth development.

9. **Hemophilia** – The hemophiliac is, first, a boy who needs tutoring in the ways of becoming a man. He needs a sense of his own worth, belief in his ability to work and achieve, and respect for independent effort. He is also a boy who must compete for and achieve these goals within the context of specifically defined activities. As the child grows up, he should be taught everything there is to know about his condition, including realistic precautions and what he must do in case of accident.

Much depends upon the father's reaction. If he accepts and shares responsibility for the care and upbringing of his son, he may reduce the mother's overwhelming sense of guilt and not deprive the boy of the masculine image he needs. If deprived of the opportunity to control his own behavior, and live as normally as is possible, he may become belligerent and rebel against his mother's restrictions. The pattern is common among hemophiliacs and most unfortunate.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
II. Role Arrangements in Family Life **Objective:** Learn to identify with the physical and social roles of the parent of the same sex. **A. Role Identity**		
1. We can learn a great deal about our future roles from our fathers and mothers.	1. Plan the year's program to make a special effort to include your father, brother or male relative or family friend. Holiday programs and performances presented by your class Special Saturday program for dads. Class-Family picnic Class-Family recreation nights 2. Ask your mother to work with you on a mother and daughter "femininity" project.	1. Suggest some of the following activities for PTA meetings this year: dance fun auction spaghetti supper wine-tasting party information meetings on curriculum, psychology, mental health, college, vocational preparation and providing for the disabled child after the parents' demise. 2. Make a scrapbook of mothers and daughters with sections for attractive clothes for all occasions, attractive hair styles, correct behavior or "etiquette", good grooming for attractive appearance.
2. Individuals learn to be masculine or feminine by emulating significant men and women. Accepting oneself, and taking pride in being a boy or a girl is a first step toward maturity.	1. Discuss one of each of the following and tell why you would like to be or act like them when you are older: 1) family members 2) neighbors or other community people 3) mass media personality 4) public figures 5) historical figures	
3. It is not always possible to specify interests, leisure activities, and family functions that are distinctly male or female.	1. List interests, leisure activities, family functions, and vocations that are engaged in by members of both sexes.	1. Discuss the family roles and vocational roles now open to men and women. (See McGraw-Hill publications' rules on equal treatment of both sexes).

BACKGROUND INFORMATION 4-6

B. Human Reproduction and Heredity

General – Families of physically disabled children often tend to "protect" them from the "facts of life". Their dependency on physical care may cause their parents to equate physical dependency with physical or emotional immaturity. A protective attitude at home and a limitation on opportunities for contacts outside the home often result in below-average information on human reproduction. The teacher must create the opportunity for a thorough and clear understanding of the processes of human reproduction without assuming any previous background of information in the child's learning.

A severe disability may affect the way a child approaches information about the conception, development, and birth of a baby. If his condition was present from birth he may wonder if something happened to hurt him or if he was destined to develop as he did. Questions may concern not only his ability to have children but also the possibility of passing his disability on to them. Not all children in the fourth through sixth grades will raise questions requiring detailed descriptions of their genetic makeup and sexual potential, nor will every teacher find it fitting to give such information in depth. A thorough background about these matters has been provided so that the teacher can deal with questions on whatever level is appropriate to the particular situation.

In choosing books and visual aids teachers must bear in mind how different the bodies of their students may be from the "typical" male or female pictured in sex education materials. (Note: Differences are usually of height, weight, bone structure, etc. Genitalia are normal unless otherwise stated with description of the disability.) In order to protect the body image of students teachers can supplement with information about what is normal for different kinds of disabilities. It should be stressed that a description of what happens to the average person is just that – an average of the development of many different types of people. Each child must learn what degree and rate of physical maturity will be normal for him. Materials stressing the importance of good medical care for mothers in order to help produce healthy babies must be qualified with the fact that good prenatal care cannot prevent many disabilities nor does poor care cause them. Questions about drugs and congenital deformities may arise from materials about prenatal care.

1. **Dysautonomia**
   1) Hereditary
   2) Sexual activity may have an adverse effect on blood pressure, pulse, etc.
   3) Stress of childbirth may be too great for women to bear safely
   4) Excessive masturbation not uncommon among boys
   5) Bodies slight in comparison to norm.

2. **Spina Bifida**
   1) Unknown origin
   2) Early menarche in girls
   3) Lack of sensation will cause diminished feeling of direct sexual stimulation. Boys may not be capable of sustaining an erection. Girls may believe that they cannot become pregnant because of lack of sensation. Sometimes incontinence necessitates the use of diapers or urine collecting devices which embarrass both sexes.
   4) Bodies will be slightly shorter than the norm but will otherwise look the same except for myelomeningocele.

3. **Muscular Dystrophy**
   1) Hereditary
   2) In later stages boys will be unable to masturbate and incapable of playing an active role in sexual intercourse
   3) Bodies will become less and less like the average as muscle wasting progresses

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
B. Human Reproduction **Objective:** Understand the basic facts of human reproduction.		
1. The cell is the basis for all life – sperm and eggs are cells.	1. Under a microscope, look at various kinds of human cells including sperm and egg cells.	1. On a human torso model of a man find the testes where the sperm cells develop and on a torso model of a woman find the ovaries where the egg cells develop.
2. Conception of a baby – The egg cell of the mother unites with the sperm cell of the father to create a new life.	1. View the film strip "Boy to Man", and "Girl to Woman" with your SNT and then make a list of the important terms in the anatomy of the male and female.	1. Make a life size drawing or clay model of each of the reproductive systems.
	2. Using a science lab model, review the anatomy and physiology of the human reproductive system.	2. On your model or drawing, point to the area (fallopian tube) where the egg and the sperm unite and where this fertilized egg then grows (uterus).
3. A fertilized egg cell grows in the mother's uterus.	1. On a large diagram of the male and female reproductive systems, draw the route of an egg cell, a sperm cell, a sperm cell entering an egg cell, and the fertilized egg cell implanting itself in the wall of the uterus.	

4. **Arthrogryposis**
   1) Unknown origin
   2) Stiffened limbs will require adjustment in sexual intercourse
   3) Affected limbs will differ in appearance from the average

5. **Congenital Amputee**
   1) Usually of unknown origin though some are the result of drugs taken by the mother during pregnancy (e.g., Thalidamide)
   2) Bodies markedly different from norm depending on the nature of malformations

6. **Osteogenesis Imperfecta**
   1) Hereditary
   2) Brittle bones may limit sexual activity though condition stabilizes with physical maturity
   3) Bodies will appear small in comparison to norm – varying degrees depending on severity of condition. Frequently broken bones take on a curved rather than straight shape

7. **Achondroplasia**
   1) Hereditary
   2) May not be sexually compatible with people of normal size
   3) Bodies diminutive in comparison to norm

9. **Hemophilia**
   1) Hereditary
   2) Bodies underdeveloped in comparison to norm.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
4. The baby grows and develops inside the mother for a period of 280 days before it is born.	1. After your teacher explains the development of a baby, review what you learned by explaining each of these words to the class: gestation, embryo, fetus, placenta, umbilical cord, amniotic sac, labor, birth, fertilization, implantation, cell division and differentiation, embryonic development, fetal development.	1. Develop cross-word puzzles using all of the new words in the unit on Human Reproduction.
	2. Elect project committees to buy and care for animals selected by them – gerbils, fish, fertilized eggs, etc.	2. At the appropriate times, observe fertilization and birth of the animals or fish and make and keep illustrated logs of their development from fertilization to birth.
	3. Appoint a committee to show films or transparencies which your teacher will supply, explaining the growth of a baby in the uterus.	3. Draw and make a plaster model of a baby growing inside its mother.
	4. Have a "Good Old Days" Day: Bring in your baby pictures and baby clothes and tell the class about the earliest memories you have.	4. Ask your mother what she remembers while you were growing inside her before you were born.
	5. Bring in recent pictures of yourself to compare to your baby pictures. Have your teacher discuss how your bodies have matured over the years, yet have remained the same person because of your unique genetic makeup.	5. Have a "Name That Baby" contest for other classes to see how many of your recent photos they can match to baby pictures. Bake a class cake as a prize – something you couldn't do as babies!

BACKGROUND INFORMATION 4-6

III. Personality

A. Positive Attitude and Positive Self-Concept

General – There is a range of opinions on the relation of a physical disability to a child's personality development.

Meng says a disabled person is different by reason of his disability, and as such, through such experiences as the necessity for undue physical exertion, pain, misfortune, fears and other factors associated with the disability itself, the handicapped person considers himself in a position of uniqueness and narcissism.

Frances Connor, in Cruickshank's *Psychology of Exceptional Children and Youth*, reviews the findings of a number of professionals to show the extent of this range.

As a result of too much parental attention or as a result of condescending attitudes on the part of society, for example, the handicapped child comes to feel inferior and unconsciously overcompensates so as to achieve psychic stability.

Michal-Smith observes that the status a physically handicapped individual has in society contributes to feelings of inadequacy, rejection, frustration, hostility, and guilt. Social perceptions of the disability accentuate feelings of social devaluation and deter the individual from making an adequate social adjustment. At times, however, the disabled person may turn this social devaluation to his own advantage, using his preceived helplessness to avoid responsibilities and to project blame for failure upon others.

Driekurs says that courage and social interest, or the lack of them, determine whether a disability permits a good social adjustment or leads to permanent failure.

Cruickshank says that "two types of problems to be observed in the handicapped child are (1) adjustment problems which might occur in the normal developmental progress of any individual who is simultaneously striving for expansion of self and for the maintenance of the self-concept already developed, and (2) adjustment problems which are solely resultant from the fact that the physical handicap is inserted between the goal and the self-desire to achieve such a goal."

Connor concludes that no specific patterns or personality types appeared to differentiate the disabled from the nondisabled group. Physically disabled children as a group do not appear to differ qualitatively in adjustment from other children. Also lacking is conclusive evidence to support the belief that mental health problems occur with greater frequency among the disabled.

Linkowski's and Dunn's "Self-Concept and Acceptance of Disability," *Rehabilitation Counseling Bulletin*, Sept. 1974 findings lend support to the two hypotheses:

> There is a positive relationship between acceptance of disability and self-esteem.
>
> There is a positive relationship between acceptance of disability and satisfaction with social relationships.

Students' Worries

Death can be a very real fear among physically disabled students.

Experiences at Human Resources School after three elementary student deaths occurred:

1. The children thought others who were out sick were also dead. Teachers

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
III. Personality **A. Positive Attitude and Positive Self-Concept** **Objective:** Appreciate all the things you can do.		
1. There are many things you can do.	1. List all the things you can do. 2. List all the things you enjoy: eating looking at listening to thinking about 3. List all the things that make you like your classmates. List the things that make you special: for example – your preferences, your opinions, your smile, your ability to tell jokes, etc. 4. List all the things you would like to do.	1. Write a composition "I'm O.K. Just As I Am." 2. Plan the school year schedule to include the following events: a health-science fair essay or poetry contest a track and field day a play or musical show a visitors' day with student-guided tours 3. Plan a class or group trip to one of the following: a department store the United Nations a baseball game a circus the zoo a farm a visit to Santa Claus 4. Next to each one, plan how you could do that or something else that would be a good substitute.

BACKGROUND INFORMATION 4-6

provided the opportunity for everyone to telephone and speak to the students who were home sick.

2. Students said it was getting "spooky".

3. There was misinformation about Muscular Dystrophy. Some thought that all those with Muscular Dystrophy died at a specific age.

4. One student thought that people in a certain teacher's class die.

Teachers answered individual students' misinformation or worries with factual information immediately when it was expressed.

They also had small group discussions on fears that the children expressed.

Teachers observed students' actions in the light of possible worries about death and emphasized the positive aspects of each day.

Adjustment problems exist. They may be overcome with the proper attitudes. Some of the problems associated with specific disabilities are listed below.

1. **Dysautonomia** – Hyperactivity usually outgrown at 12 or 13. Dizziness, vomiting cause constant fear of illness and fear of going into new situations and the reverse is often true. They are slow starters in the morning and the physiological problems create anxiety in the morning. Poor coordination – less opportunity for participating in games, etc. Although friendly with each other, children with dysautonomia have slow social development and are deficient in adaptive reactions to change.

The child with dysautonomia experiences bewilderment over lack of control over himself and and his "all-or-none" reaction to emotional stimuli. A particularly upsetting disturbance in autonomic functions is the tendency to vomit. It is not always induced by emotional problems. There may be no precipitating factor apparent. When such vomiting attacks start there is usually marked personality change. The child may become withdrawn and disagreeable, may rub his stomach as if in pain, may whine or cry. Sometimes during these periods they try to hurt themselves. The attack may last two or three days. Vomiting may be controlled by medication, but personality change may last the full period. When the attack is over, the child resumes normal personality.

2. **Spina Bifida** – Parental anxiety combines with children's anxiety knowing they are going for major surgery. Others' anxieties may become contagious. They often overhear many details which sound frightening.

3. **Muscular Dystrophy** – As Connor, Rusalem, and Cruickshank point out, most personality problems in crippled children are part of adjustive attempts to integrate the disabling condition into the living space rather than being an inherent part of the disability.

4. **Arthrogryposis** – Demanding because of inability to help themselves due to their particular deformity. Because of dependency they may be forced into being demanding. Encourage and help them to develop self-confidence and capability in things they can do.

6. **Osteogenesis Imperfecta** – There is sensitivity about deformities of legs. Body image problem, "How we appear to ourselves and how we appear" is most important. They feel that they make more impressive figure sitting down than standing on short legs or on crutches and having people tower over them.

Child becomes too heavy to be carried and must depend on wheelchair and then there are physical barriers – steep hills, rough terrain, steps, etc. Rage at times because of dependency on others.

Should be made as mobile as possible – to get out frustrations – let arms swing (on ballbearing feeder arms). Knowing that they will improve can help them adjust. Help them to accept themselves as they are.

Guide and channel verbal energy. Most seem to have good verbal intelligence.

7. **Achondroplasia** – People gear their reactions and expectancies of the dwarf first to his size and not his age. The more a dwarf is babied, the greater is the immaturity or lag in social-behavioral and personality development.

8. **Congenital Cardiac Conditions** – Because of many precautions taken against infections, over-exertion, and generally keeping the child from frustrations ever since birth, the child may be very spoiled, demanding, and easily upset or somewhat hypochondriacal. They may be called "sissies" by their peers.

Heart Disease may affect a child's personality development. If the condition is congenital, parents may feel responsible. The guilt this engenders may cause

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
2. I can deal with my feelings.	1. Choose one of the following activities to help you become more aware of your feelings: a) Read and discuss a poem such as "I'm Like Me." b) Write a poem or story describing a strong feeling that has surprised you. c) Have a rap session to figure out why you or someone you know sometimes does "mean" things. d) Have each student bring in part of a story which requires a decision and ask each student in the group to write his own ending. 2. Investigate the feeling of fear. Find out how fear can be helpful to human beings. Ask everyone to make an anonymous list of the things they are afraid of.	1. Then read the endings to the group and discuss all the possible endings to the story. 2. After discussing the lists try to decide whether it's true that everyone is afraid of something at some time.

BACKGROUND INFORMATION 4-6

them to reject the child overtly and covertly (through overprotection and indulgence) – an attempt to compensate for "wronging" him . . . In either case, developing child often responds to the underlying hostility with a negative self-image and low self-esteem, for children with cardiac disease are strongly influenced by parental perceptions or misperceptions.

Because child feels "different" from his peers, his experiences become more restricted; consequently, if very little demanded of him, he may conclude that he is "worthless." He may drop out of school or be in danger of dropping out of life altogether.

9. **Hemophilia** – Reactions that may be anticipated because of frequent bleeding, physical pain, and repeated separations from their family are strong feelings of being different, and therefore inferior.

One way to promote healthy adaptation is to provide the child with knowledge concerning his condition and methods of assisting in his own care. He must learn to report injuries and bleeding.

Provision of knowledge enables the hemophiliac child to control his behavior by reason and judgment rather than by fear. Fear is likely to result in rebellious activity or a "giving up" response.

Rather than permit fear, withdrawal, or passivity, he must be encouraged to participate fully in accepting peer activities at school and play. Depending upon the severity of his hemophilia, he may engage in such sports as golf, tennis, swimming, archery, and boating, as well as in more sedentary interests such as chess, stamp collecting, building models, reading, or other pastimes related to his interests. It is common therapeutic knowledge that healthy physical activity helps to reduce anxiety and emotional stress. Some clinical findings suggest fewer hemorrhages among physically active hemophiliacs. In some hemophiliacs who learned to compete aggressively, the frequency of bleeding episodes has diminished.

Vital factor to adjustment is formal education. It is important to discipline a hemophiliac child as any other, or he may use this to manipulate adults. Non-physical forms of punishment can be used.

B. Improving Personality through Communication

General – Since peer-group relationships are vital to normal social development, every opportunity must be provided by the teacher (and the parents) to allow and encourage children to play and socialize with their age peers of both sexes in pre-adolescent social events.

Let students have the experience of achieving recognition by rewarding them for cooperation, personality, good deeds, interest in others, etc.

Desensitization is needed for disabled students who are hurt or angry when another child asks about their physical problems or calls them a "cripple."

General – Disabled children may have to overcome visible differences from able bodied peers that tend to strain initial meetings. It will be helpful for them to be prepared to explain their disabilities simply and clearly without embarrassment or bitterness. In this way the handicapped child can help potential friends to relax with him. Questions, even from unintroduced strangers who don't need a detailed reply, have to be handled by the child with a handicap. Children can prepare appropriate answers for various situations. Teachers can help them to decide how much information they should give, stressing how openness and cheerfulness will help to make a friend. A child who cannot participate in contact sports for fear of injuring himself can explain his refusal without appearing unfriendly or babyish about hurting himself. This kind of explanation can also be role-played in advance.

1. **Dysautonomia** – Children have a tendency to be immature emotionally and easily upset by what others consider minor matters that only a baby would mind. In some cases their insistence on having their own way bothers friends who will not tolerate tears, vomiting or tantrums that over-indulgent parents submit to. An irresponsible attitude toward toilet training can result in lost friendships when a child's odor is persistently unpleasant. Drooling can be offensive to peers. Back braces to correct scoliosis may have to be explained.

2. **Spina Bifida** – Since their bodies are close to "normal" in size and shape, children may be more readily accepted by nondisabled peers. Incontinence, though not immediately noticeable, can be offensive if carelessness results in odor. After a friendship is formed questions about

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
B. Improving Personality through Communication. **Objective:** Practice communicating with friends and strangers.		
1. Developing your abilities in communication and in social "know-how" will improve your ability to get along with others.	1. As a class or club project read plays about great heroes. Stage and perform your favorites for parent meetings or assemblies. Form a drama club. Give a wheelchair square dance, or a rock dance. Form a dance club to learn how to "dance" in a wheelchair.	1. Plan games and events for parties for each of these occasions: Halloween, Valentine's Day, Christmas or Chanukah. Form committees and give the parties. Each week, elect a class "king" and "queen" honoring them for cooperation, personality, good ideas, good deeds, interest in others, etc.
2. Seeing things from the other person's point of view helps us to communicate with him.	1. Role-play the part of a non-disabled student who just met you and who does not know whether he might hurt you if he plays some gym activity with you.	
3. Advance practice can help one learn to cope with situations which require positive communication.	1. Improvise and act out your reactions in the following situations: Someone comes up and says "What's the matter with you?" or "Why can't you walk?" or "Why do you wear those braces or use those crutches?"	

BACKGROUND INFORMATION 4-6

diapers or collecting devices may arise. Braces, crutches and wheelchairs may bring questions from peers who cannot see anything wrong.

3. **Muscular Dystrophy** – Until very late stages, physical differences from peers are not so severe as to cause questions from others, but obvious lack of muscular strength may have to be explained. Children are not likely to be first choice sports participants and cannot join physical activities as they did before their disability progressed. Those in later stages may be very withdrawn and shy away from social activities.

4. **Arthrogryposis** – Children may not be able to participate in all sports, but can compensate for their stiffened joints and join their peers in many games. They may need help with dressing for sports activities or toileting and should be prepared to explain why they cannot do these things for themselves.

5. **Congenital Limb Deformities** – If their deformities are clearly visible, children will be faced with questions wherever they go and must learn to cope with ignorant, rude strangers. Even a potential friend may want to know why or how a deformity came to be or be interested in the function of a prosthesis, so rehearsal of such questions and appropriate answers can be most helpful.

6. **Osteogenesis Imperfecta** – Children have a responsibility to protect themselves against injury, especially when participating in sports activities. They must learn to combine reasonable caution with a willingness to be a part of group activities. It may help to rehearse a sensible refusal to some rough contact sport, suggesting an alternate role for participation (e.g., score keeper, time keeper, etc.).

7. **Achondroplasia** – Children may have to prove that they are not babies despite their diminutive size. They can help those less able than themselves (e.g., MD's) and win friends through unselfish assistance to classmates. Peers of "normal" size may have to be discouraged from babying them, and strangers may repeatedly cause offense by taking them for younger than they are.

8. **Cardiac** – Like those with brittle bones and bleeding conditions, children must learn to refuse dangerous activities gracefully. This may be a problem when physical appearance does not indicate any need for caution. If the child has the cyanotic type congenital cardiac defect, the child will have to explain why his lips and nails are blue. Assiting with a simple explanation will help the child to cope with the problem.

9. **Hemophilia** – Children who bleed uncontrollably, like those with defective hearts and brittle bones, will have to refuse contact sports that could result in injury. They must be able to explain why they cannot play normally with new friends so that they do not appear unfriendly or disinterested in their peers.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
	2. Create roles for realistic situations which you want practice in coping with: Ask someone to come to your house over the weekend. Include suggestions for things you could do together. Have a conversation with someone you've met from another school. Telephone a classmate to discuss going to some school extra-curricular activity.	2. Form committees to practice your communication skills by one of the following: An original stage production. A puppet show. Make an audio cassette to accompany an exhibit or a film strip. Write a letter to a friend who has moved or who is sick. Write a thank-you note to someone who has helped your class. Have a rap session on how to relax and be yourself.

C. **Experiencing Independence**

1. **Dysautonomia** – The child who is deficient in adaptive reactions to change may have a great deal to fear when faced with an independent trip.

2. **Spina Bifida** – By the time a child is ready to go on a field trip he should have taken over the responsibility for his liquid intake and bathroom visits. This can be taken care of by parents or school nurses, but should eventually be a vital part of his responsibility for his own body.

Up to 15 years ago only 20% lived beyond 30 or 40 years. Most died of urinary tract infections. Help for independence must start *very* early. Procedures for bowel and bladder continence, etc.

3. **Muscular Dystrophy** – Encouraging a child at this age to walk as long as is safe will prolong his feelings of independence. However, when safety is more important, the child should be encouraged to use a walker or wheelchair and propel them independently. The child will see that it is easier to keep up with his peers and is less tiring. Emphasis on the positives at this time is very important and de-emphasis on the weakening of the body.

5. **Congenital Amputee** – An independent trip can serve as a goal for the child who must persevere through hospitalizations and therapy in order to manage prosthetic equipment alone.

7. **Achondroplasia** – Since he is independent in activities of daily living, the achondroplasic can plan to care for himself once architectural barriers (tubs, toilets, sinks, vehicle steps and seats, etc.) are taken into consideration during planning.

8. **Congenital Cardiac Conditions** – Field trips and outings must be planned with awareness of the cardiac's physical limitations.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
C. Experiencing Independence **Objective:** Increase the number of things you can do.		
1. Exposure to a variety of everyday experiences (as a child) prepares one to cope with the adult world.	1. Prepare for a trip by planning what you need to know about a place. Call or write to ask about requirements and times for entrance, accessibility to entrances and restrooms. Make a list and then pack a bag with the special clothes, towels, shoes, you will need. Check with the bus, get parents' permission slips, etc.	1. Take a field trip to: a) a department store b) church c) museum d) library e) park f) beach Report on what you saw, how you managed, and what to prepare for a future visit. Plan with your parents to go shopping, with them. Go with them. Determine to manage the architectural and natural barriers yourself as well as possible.
2. Doing things for yourself will make you more independent.	1. Read *A Big Ball of String.* Plan ways of rearranging your room that would help you to do things and get things yourself. 2. Give yourself a check mark for each day you get out and put away your own school clothes and books. 3. Send for booklets that give you ideas on how to put on articles of clothing that are difficult for you. (Also see *Self Help Devices,* by Edward Lowman and Howard Rusk)	1. Draw a plan of your rearranged room – make a chart listing how many things you can now get for yourself. 3. Make a chart giving yourself a check for each day you put on one of the articles of clothing that are difficult for you.

D. "Modeling" – Learning from Older Disabled Students

General – If a younger disabled student can relate to an older, successful student with a disability, he has a model or image to follow. He would also feel less deficient than when he compares himself to his non-disabled brothers or sisters. Contact with a helpful disabled teenager could reinforce his optimism and help him to feel that he too can "make it."

The mutual benefit accruing to the older student should not be overlooked either. He can have feelings of accomplishment when he helps a younger, disabled child to progress.

Field day can give disabled students a feeling of pride in what they accomplish. It can be a culminating term activity in which each student has a part. Each one can participate in an event in which he has practiced and can succeed. Each one should also be included in team games to achieve a feeling of being worthwhile to the group.

3. **Muscular Dystrophy** – Planning for "buddy" days or class exchanges must take into consideration the helplessness of the older MD student as it relates to both his ability to cope with young children and his condition as an example of the disease progression.

5. **Congenital Amputees** – Helping a young child who is unaware of or freely accepts his disfigurement can serve as a morale boost to a deformed student who must constantly cope with his obvious differences from the norm.

6. **Osteogenesis Imperfecta** – A younger child may receive needed encouragement from someone who has passed through the very fracture-prone years and begun to participate in more physical activities. The older student may feel less sorry for himself when reminded of how improved his condition is in comparison to his young friends.

8. **Congenital Cardiac Conditions** – Working with small children may or may not be a recommended activity depending on the degree of strength and endurance demanded by the particular situation.

9. **Hemophilia** – The accomplishments of older hemophiliacs can give encouragement to youngsters trying to cope with the disability. The older students can gain a feeling of self-worth and confidence when reminded of their achievements and given the opportunity to "father" a younger child.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
D. Modeling – Following Older Disabled Students **Objective**: Learn how an older disabled student succeeds in school.		
1. Learning how older students with disabilities accomplish their school work and engage in sports events could give us a model to follow.	1. Ask your teacher's help in writing a letter to a disabled student in a senior high class. Ask him if he could come to your class one afternoon a week to be your "buddy" and show you how he does things (lessons, games, sports) in better ways.	1. The older student could then return the invitation by inviting the younger ones to be guests at a recreation event such as a wheelchair basketball game.
	2. With your teacher's help decide on three activities, sports or games that you would like to improve at. Each day at lunch period or gym, practice this.	2. Have a wheelchair track and field day with team and individual contests, games.

IV. Growing Toward the Teen Years

A. Individual Patterns of Physical, Social, and Emotional Development

General – It is important for physically disabled young people to know about the physical, emotional and social changes in the average boy and girl since they may not have too much contact with "normal" children. From this knowledge they can appreciate the basic patterns that they have in common with everyone else and realize that they are "normal" in most aspects of their lives. They should also be helped to realize that height and weight is highly individual and that their growth pattern may be "normal" when compared with other people with their disability.

It is important to include the parents in this instruction. Many parents have not given any thought to the fact that their pre-adolescent children will be developing sexually. Parents should be invited to preview audio-visual material, discuss contents of the curriculum and be included in the learning activities of their children.

There is some comfort for physically disabled pre-adolescents to know that doubts and worries are experienced by all young people. Some physical disabilities are associated with earlier or later maturation and this causes worry to the young person involved.

1. **Dysautonomia** – Boys and girls often mature later both physically and emotionally. Puberty is commonly delayed in both males and females. About 50% of the girls will not have their menarche until over 16 years of age. Puberty does not have as dramatic an onset in the males as the female but it is also delayed. There is fairly good correlation between physical appearance, bone age and the onset of puberty. In those individuals who are extremely thin and small it is more likely that the bone age and puberty will be lagging. Puberty was not begun until 19 years of age in some individuals. However, primary and secondary sex characteristics eventually develop in both sexes.

2. **Spina Bifida** – The girls start to mature physically at a younger age than "normal" girls. They can begin their physical changes at 9 years or even late in their 8th year. Parents are often unaware of sexual development of adolescents. Because of parents changing diapers of 12 years olds, they do not consider the adolescent as maturing and do not think of accepting their growth.

3. **Muscular Dystrophy** – One stage of the progression of MD involves deposit of fat in the muscle tissue, and for a period of time the children look

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
IV. Growing Toward the Teen Years		
A. Individual Patterns of Physical, Social and Emotional Development.		
Objective: Understand and accept the individuality of patterns of development.		
1. Physical, social, and emotional changes at puberty lead to manhood and womanhood.	1. In a coordinated science and health project, investigate and report on how some of the body's growth processes are controlled by the endocrine glands, which secrete chemicals known as hormones.	1. View films on the following topics with the school nurse-teacher and then write any questions you may have on cards: menstruation (menarche), nocturnal emissions, secondary sex characteristics of boys and girls, sexual feelings, masturbation.
	2. Explain each of the following secondary sex characteristics which develop with the approach of the teen years: pubic hair, enlargement of genitals, voice change in boys, change in body contors, development of breasts in girls, onset of menstruation in girls.	
	3. Discuss which of the following psychological characteristics you have noticed in your friends who are approaching teenage: mood fluctuation, assertion of independence from adults, need for approval, awareness of the opposite sex.	
2. Physical and emotional changes affect attitudes toward the opposite sex.	1. Discuss friendship of boys with boys, girls with girls, and boys with girls. Have a girls' committee make a list of "What I Like Best About Boys" and a boys' committee make a list of "What I Like Best About Girls."	1. Put both lists on a blackboard side-by-side and note the similarities and differences in the lists.

fatter than the average child their age. As wasting continues, they get thinner and more emaciated in appearance.

4. **Arthrogryposis.** – The need for excessive physical dependence because of inflexible joints causes a great deal of frustration at a time when young people are trying to exert their independence. Since they have a full life expectancy, they have all the everyday problems plus limitations of the disability. Acceptance by peers causes worries for them because they cannot "keep up" with the average active pre-teenager. Still have to be cared for (dressed, helped into bed, tub, etc.).

5. **Congenital Amputee** – Usually the bodies and minds develop at an average age and the lack of a limb is not associated with any delay in maturation.

6. **Osteogenesis Imperfecta** – Children are often smaller than average height. Girls are often later in physical maturation.

7. **Achondroplasia** – Children will be considerably smaller than average height throughout their lives. They also continue to look like little children even after maturing. A dwarf, if given phony hopes and predictions about growing to normal height, is hindered, not helped, in coming to terms with his problem in life. He does not need to be robbed of all hope, however, since medical predictions are statistical ones. They need to know facts about their growth and development so they know that fads will not make them grow. (They get hormones early in life – not later. It wouldn't do them any good later.) Even though they can walk they sometimes prefer to use a wheelchair because it puts them at "normal" height. At work they will have to walk, so they need to be encouraged to walk to strengthen legs during growing years. Sitting with knees out and feet toward one another might cause bowing effect.

8. **Congenital Cardiac Conditions** – Children often look thin and undernourished due to inadequate circulation. As adolescence approaches, some of the previous physical problems not so apparent cause more complications. As the body matures, the heart has to work harder and can show more of the deficits.

9. **Hemophilia** – If they have been well cared for, children with hemophilia may have a normal appearance while developing physically. If they have been very protected they may be less mature emotionally.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
3. Changes occur in the pre-adolescent period. Girls begin pre-adolescent growth and puberty at a younger age than boys.	1. Keep height and weight records for the term. Make graphs on personal individual growth.	1. Explain how accepting one's self and taking pride in being either a boy or a girl is a step toward maturity.
4. Growth and development takes place regardless of your physical disability. A wide range of growth patterns is to be expected.	1. Invite the school nurse-teacher to discuss the maturation process with you. View film strips such as "Learning about Sex" and "There's a New You Coming" (boys and girls separated for viewing). Each group will see the film about the other sex. In the discussion following each presentation, ask the SNT to discuss the differences in the rates of physical and emotional growth and the additional responsibilities this growth brings.	1. List the signs of your own physical and emotional maturation at this time. Then list the changes you can expect in the future. Observe that the same predictable pattern of changes occurs for all, but with variations in age of occurrence.
	2. Take a pre-test on the vocabulary of body parts used in teaching growth and development: abdomen breasts axillary hair penis anus hormones pubic hair uterus vagina scrotum bladder sperm testes voice box	2. Review the meanings of all the new or special words used in the lesson. Make up a 10 word vocabulary test for your neighbor and exchange tests with him. Review this procedure until you have learned 80% of the new words.
5. Feelings of self-doubt and worries about slow or rapid maturing are experienced by most adolescents.	1. Ask everyone in the class to list, on unsigned cards, 10 things that they are worried about or embarrassed about at this time in their lives.	1. Under the direction of your teacher, have two class representatives combine the lists, noting which worries are felt by most of the class members. Then invite the psychologist or guidance counselor to discuss these worries with the class.

BACKGROUND INFORMATION 4-6

B. PEER RELATIONSHIPS

In class the teacher should encourage a situation in which non-disabled and disabled students can plan activities together, especially those which the disabled student can do well – so that barriers of non-understanding can break down on both sides. In the early years, children communicate through play. Let the activities be fun and of the game type. In the classroom it may be necessary to design activities to force interaction, at first, especially in small groups. In addition to health activities mutually enjoyable activities such as art projects, checker or chess tournaments, photography club or sports quizzes could be run by the students. The children need the opportunity to communicate with each other on the basis of the mutual interest or project.

During pre-adolescence, when peer-group identification takes on such great importance, the physically disabled child experiences:

a) the need for opportunities to meet more friends and then to be able to "get together" with them frequently.

b) a desire to show non-disabled peers that he can compete and win in some areas

c) worries about being rejected or avoided by non-disabled peers who think a disability makes a person "different"

d) lack of the social experience of interacting with other children as equals, and so needs practice in communicating about his interests, opinions and ideas. To do this he needs to find a common ground of interests with others his age.

It is suggested that the groups meet on a regular basis over a period of time to give them a sufficient time to really get to know each other as people.

The teacher can encourage the communication by pairing appropriate children and providing resources with which they can work and play.

A project such as this was carried on between intermediate students at Human Resources School and a local public school. The orientation of the disabled students was to try to prove they were "better" by choosing activities at which they could win such as wheelchair basketball. The rap sessions with the psychologist afterwards were aimed at helping them to understand that while you may find it necessary to prove yourself in the business world, in being a friend you do not have to be anything but yourself.

They noticed two initial reactions among the non-disabled students. They either avoided some disabled students or else they were over-protective and wanted to help them too much. Discussions helped them to realize that this was a positive reaction and a way of trying to show friendship. At future meetings both groups were more at ease and were able to relate to each other on the basis of their mutual interests and personality affinities.

Inter-school Project with Non-disabled

The peer-to-peer program provided the opportunity for able and disabled to work together on activities which both could do:

Participation in safety health education activities developed the previous year
Cooking together
Library research projects
Swimming

Discussions brought out feelings about the need to compete, and, under the guidance of the psychologist, observations by the disabled students that the best communication with non-disabled came at lunch or in talking over their activities or comparing opinions on big league sports or TV programs, not during competitive times.

Pre- and post-project meetings were held for the parents, the last meeting being a barbecue and reception for all the parents and children involved in the project.

Conclusions showed that Human Resources School students did not show much change in attitudes toward the disabled because they had already scored high in positive attitudes and expectations. The non-disabled students did show positive changes in attitudes toward the disabled.

Other Friendship Opportunities

Human Resources School provided opportunities to meet as many school friends as possible by having flexible intergrouping for learning among 55 intermediate-level students in a very large adapted open classroom.

In addition students from several other schools were invited to periodically attend holiday entertainments.

Conclusions show that all 55 intermediate-level students increased the number of their school friends from an average of 12 to an average of 25. Observations of each child showed that they all knew each other by name, spoke to and interacted with about 25 others several times a week, wrote cards and telephoned each other when they were absent.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
IV. Growing Toward the Teen Years B. Peer Relationships **Objective:** Learn to develop peer relationships. 1. Taking every opportunity to meet other children, to "act like a friend" and share common interests will increase the possibility of making friends.	1. Discuss the saying "To have a friend you must be a friend." Ask one student to list the ways for "being a friend" during the discussion. 2. Invite another class (from another school if possible) to engage in a health project with your class. Form committees to: send invitations act as hosts or guides plan and prepare a lunch menu plan two good activities for two groups to work together on 3. Get together with the other group to write and present a skit or to write a creative poetry booklet, or to give a slide presentation which you organize and narrate.	1. Rate yourself in a daily notebook on the number of times each day that you act like a friend to someone. 2. Plan to return the visit. Make a list of things to check including the following: Will the bus be available? Is the entrance to the school accessible? Is the school on one floor or are there elevators? Can lunch be bought or brought? Are the toilets accessible? Can the school nurse give me my medication if necessary? 3. Have a rap session with the visiting class on how you felt about meeting each other before and after you exchanged visits.

Mental Health & Family Life Education Module

Grades 7 - 9

Mental Health 7-9

Special Topics in this Module	Objectives
I. Why We Do The Things We Do	
A. Positive Self-Concept	Recognize your own abilities.
B. Handling Frustrations and Solving Problems	Learn appropriate ways to handle frustrations and solve problems.
C. Using Leisure Time to Promote Well-Being	Develop hobbies which can be continued in the future.
II. Learning More About Ourselves	
A. Teen-Age Concerns	Realize that teen-agers have many common concerns.
B. Values	Become aware of the basic values which guide your conduct.
C. Realistic Goal-Planning	Learn what tasks are involved in a profession or job you would like and investigate the personal abilities required for that job.
III. Dimensions of Maturity	
A. Physical Maturity and Adolescent Development	Understand the wide variety of physical changes in adolescence.
B. Emotional Maturity	
1. Communicating	Take the initiative in communicating your needs and giving factual information about your disability.
a. Asking and Refusing Help	
b. Educating Others about Disability	
2. Attitudes Toward Oneself and Others	Work to improve attitudes toward disability.
3. Making and Keeping Friends	Learn ways of making and keeping friends.
4. Accepting Responsibility	Accept responsibility for your own care and school work.
IV. Interpersonal and Boy-Girl Relationships During Adolescence	During adolescence increase participation in activities which expand opportunities for interpersonal relationships.

BACKGROUND INFORMATION 7-9

I. Why We Do the Things We Do

A. Positive Self-Concept

General – Emphasizing the fact that everyone has certain strong points and helping students to adopt a positive attitude by recognizing their own ability in an honest way substitutes positive for negative attitudes.

Self-concept and self-image are also related to a student's academic achievement. Through individualized diagnostic and prescriptive teaching the school can help the disabled student begin at the instructional level and in areas at which he can achieve success. A success experience can reinforce the self-concept. Then, by using his strengths as a basis for remediating his weaknesses, the teacher can help the student to continue to succeed.

1. **Dysautonomia** – Emotional problems can be overcome with encouragement of good self-image. Encourage independence in the student in any way possible. He can be responsible for whatever treatment is necessary during the school day, i.e., IPPB therapy and breathing exercises. Let him schedule the day so the external environment can be more predictable than his own internal environment.

2. **Spina Bifida** – Often feels less adequate and experiences anxiety and depression. Focus his attention on his assets. Encourage as much independence as possible.

3. **Muscular Dystrophy** – During teen years there is a period of depression due to the awareness of the reality of their situation – (Duchenne Muscular Dystrophy is a progressive disease). Encourage independent activities for as long as is physically possible. Using a motorized wheelchair for independent mobility is a good boost for the student's ego and feeling of self-worth.

6. **Osteogenesis Imperfecta** – If they can walk around, they don't identify as disabled. However, those with very fragile bones are very small and immobile. During adolescence fracturing occurs less often. Therefore the student's outlook improves. At this age there is less fear of new situations, which gives the student more incentive and ambition for exploration. The student's personality does not seem to be affected one way or another.

8. **Congenital Cardiac Conditions** – These students experience difficulty recognizing their abilities because during childhood they have been physically protected from many situations and not allowed much freedom. To the best of their physical capabilities, these students should be encouraged to do independent thinking and exploration.

9. **Hemophilia** – Some adolescent hemophiliacs whose parents are overprotective seem deliberately to engage in risky activities. It is misleading to speak of the hemophiliac as accident-prone. Rather, it is as if be boldly denies his illness and foolhardily courts disaster by repeatedly testing his vulnerability. Apart from the physical dangers, such rebellion generates tension and emotional strain. Although no definite cause-and-effect relationship has been demonstrated between emotional stress and increased bleeding episodes, the two are commonplace among hemophiliacs. Encourage involvement in program of self-infusion of the Anti-Hemolytic Factor which a teenage hemophiliac can handle and which gives them a new freedom and control of their situation.

B. Handling Frustrations and Solving Problems

General – Disabled students often are not used to taking initiative. They don't know how to express preferences and don't have experience in expressing or asking for what they want.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
I. Why We Do the Things We Do.		
A. Positive Self-Concept		
Objective: Recognize your own abilities.		
1. Recognizing one's own abilities helps one to appreciate one's own worth.	1. List all the abilities and good points you know about yourself. Form a small group and have everyone in the group tell you all the things they like about you.	1. Instead of rating yourself, rate your traits. Make a rating scale on which you evaluate your traits. Next to each one write one way to improve that trait. Then discuss this advice given by Albert Ellis: "Accept yourself, your aliveness, your existence, and determine to have as much joy out of life as you could possibly have during this existence."
B. Handling Frustrations and Solving Problems.		
Objective: Learn appropriate ways to handle frustrations and solve problems.		
1. There are appropriate ways of handling frustration, problems, and boredom.	1. List appropriate and inappropriate ways of dealing with anger or frustration. Discuss the topic "Frustration May Lead to Disruption or Growth. How?"	1. Discuss why each of the following would be an appropriate or inappropriate way of dealing with a man's anger at his boss: **Inappropriate –** Take it out on the family. Go to a bar and get drunk. Punch the boss in the nose. **Appropriate –** Have a quiet talk with the boss. Get some fresh air and think over such possibilities as accepting the situation until you can make a change. Talk it over with a friend. Plan to get a new job.

BACKGROUND INFORMATION 7-9

A decision-making model – The more alternative ways a person can develop to satisfy needs constructively, the better frustrations can be handled. He also needs help in (1) identifying some of the sources of his frustrations and (2) acquiring skill in dealing with them in ways that enhance his feelings of self-respect, security, and personal significance.

Two common responses of "normal" to "abnormal" people are revulsion (headwaiters "hide" you) and good luck bearers (people want to touch or give money). There is often an assumption that physically handicapped people are also mentally incompetent. People talk to their companion. They are treated as though they don't exist. There is also a myth that all handicapped are perpetually sweet and cheerful. Crippled children arouse great emotional responses in people because their vulnerability elicits a desire to care for them. But people expect adults to be sweet, etc., and find normal defenses objectionable. Then they treat them as "invisible men". Thus adults may develop a tendency to be defiant, to express themselves.

Help them accept themselves as they are. Help them to accept that the normal reaction is one of frustration. Teach them how to deal with it so they can live with themselves since they can't change the way it is. Make the best of the disability by emphasizing ability.

Examples of environmental frustration- educing accommodations are:

1. considerations in the home that take into account the special needs of each person.
2. school curricula geared to individual and group differences
3. architectural features that fit varying physical attributes of people
4. legislation on behalf of persons with disabilities
5. social attitudes of acceptance, etc.

1. **Dysautonomia** – Parents may be less strict with their dysautonomic children and not want to frustrate them. Later in life the teenager will be faced with inevitable frustrations and will need to develop ways of coping with them.

The dysautonomic adolescent may develop various defense mechanisms. All defense mechanisms are acceptable, if they help an individual to function well. They are only bad if the adolescent becomes so completely unrealistic that the defense is being used in such a way that it interferes with function.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
	2. Discuss what boredom really means: for example – Need for attention? Need for reassurance from parents? Lack of leisure activities? Lack of a plan for the future?	2. Make a list of activities you really enjoy. Make a list of other solutions to boredom. (ex. helping others) Write a paragraph on: "When I Feel Bored I Can _____".
2. Knowledge and application of problem-solving methods enable one to take a constructive approach to making decisions and handling frustrations.	1. Learn about the following methods of dealing with problems: a) Direct Attack: seeing the problem analyzing weakness and strengths working toward a goal achieving success b) Detour: change tactics or goal compensation – substitute another activity or satisfaction c) Retreat – regression: rationalization – alibis and excuses daydreaming – constructive escapism think about it and wait	1. Analyze the way you handled a problem you encountered recently.
	2. Choose one problem you have and try to deal with it by following these steps in meeting problems constructively: a) recognize whether a real problem exists b) face the problem c) seek the cause d) decide upon a goal or course of action e) begin working in a positive way to carry out the plan for solving the problem.	2. Explain how you applied these steps in dealing with a problem related to (or caused by) your disability.

BACKGROUND INFORMATION 7-9

3. **Muscular Dystrophy** – Frustrations and anger must be dealt with in non-violent ways since movement is severely restricted for the MD student. Let him use special devices such as "feeder arms" that work on a ball bearing joint for arm movement.

5. **Congenital Amputee** – Anger and frustration resulting from physical discomfort of prosthetic devices, corrective surgery, and physical therapy, as well as emotional strain of social acceptance, must be dealt with in a satisfactory way by the deformed child.

6. **Osteogenesis Imperfecta** – Dealing with frustration is very pertinent for the student with OI. Physically, he should be made as mobile as possible to get out frustrations. Physical problems, difficult as they may be, are felt to be easier to deal with than the problems and frustrations imposed by others: chronic curiosity and staring.

Emotional anger may show resentment. Need help with feelings of personal worth and achivement because of physical appearance being unattractive. For feelings of worth, practice attacking problems realistically, realizing what he cannot be because of physical limitations. Wheelchair basketball, weight-lifting may be possible for older adolescents who have strong arms.

7. **Achondroplasia** – Constant babying and being mistaken for a youngster can add frustration to that caused by limitations in height. People seem not to notice below eye level and thus don't notice them in crowds, on subways, etc. Thus the "outside world" can become a very frustrating place for people with diminutive stature.

8. **Congenital Cardiac Conditions** – Non-aggressive ways of coping with frustrations and anger must be found, since emotional upset or over-exertion could harm him physically. Constant limits on activities can be a source of such frustrations for children who appear normal and want to keep up with peers. The cardiac child who is not feeling limited by his condition may become very frustrated and angry when he is told he cannot do a particular activity.

9. **Hemophilia** – Have to learn how to deal with emotions. Since they shouldn't demonstrate anger by physical force or aggression, they need to channel aggressive feelings and verbalize more. In adolescence, since there is more stress on athletics, boys may be teased if they cannot participate. This may put more peer pressure on a hemophiliac. With growth at adolescence there seem to be more episodes of bleeding. There is sometimes brain damage from cerebral hemorrhage. Social effect – others might withdraw from contact with the hemophiliac for fear of causing injury by aggressive behavior or from lack of knowledge about the physical problems.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
	3. Try to make a decision on a problem in which both alternatives are unattractive or both are really good by following these steps: a) State the problem b) Then list all the facts (provable) related to it c) See if any can be changed d) Draw a conclusion e) Carry out the conclusion f) If not successful, repeat steps, trying another conclusion.	
C. Using Leisure Time to Promote Well-Being **Objective:** Develop hobbies which can be continued in the future.		
1. Since recreation promotes relaxation and fitness, recreational activities and hobbies can be developed to provide present and future emotional and physical well-being.	1. Investigate two of the following hobbies and report to the class on the basic knowledge and equipment needed for a beginner. Tell what clubs or groups having this hobby could be attended or contacted by mail. Hobbies and recreational activities to investigate: art media - painting, ceramics printing checkers, chess collecting – stamps, coins, flags photography creative writing reading stargazing bird watching knitting crewel crocheting embroidering rug making flower arranging.	

BACKGROUND INFORMATION 7-9

II. Learning More About Ourselves

A. Teenage Concerns

General – Disabled students want to be assured of their "normality". They want to know how the normal feelings and behaviors of non-disabled teenagers compare with their feelings and behaviors.

Emphasize normal growth and development. Chronically ill children do not have a background in this since parents and physicians have usually concentrated on the disability.

Students in junior high classes at Human Resources School requested discussions about the following subjects:

General:

1. School and teacher aides (volunteers) – too much protection from both
2. Parents
3. Death
4. Anatomy
5. Friendships
6. Babies – (Birth of –) film
7. Sex
8. Dating
9. Separate health classes into age groups instead of grade level.
10. Character
11. Everyday problems
12. Meeting new friends
13. Afraid to ask questions – want to discuss "stuff with parents here"
14. Money
15. Related to people in general
16. Disability of others in the class
17. Life
18. Women
19. Pollution
20. Mental Illness
21. "What shall we do with ourselves? How do we get transportation?"
22. Overweight
23. "How to become more respected in my family"
24. Too much emphasis on physical disability
25. Facing the world's problems

Related to Disability

1. Discuss Dysautonomia
2. Discuss Muscular Dystrophy and new findings (hope)
3. Possibility of sexual contact with Spina Bifida – open discussion
4. Genetics (will children inherit condition?)
5. Open discussion on disabilities
6. Meeting with parents, health staff and students
7. How you would have sex with an osteotomy (bag attached to abdomen for collection of urine)
8. Being teased
9. How to live when you are grown-up if you are weak
10. "Some people don't like to play with me because they're afraid they'll do something wrong"
11. Can I have children?
12. How to feel better about being short
13. Dependency on other people

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
II Learning More About Ourselves **A. Teenage Concerns** **Objective:** Realize that teenagers have many common concerns. 1. Teenagers have many common concerns.	Have a rap session on: How well do we know ourselves? How do we get along with our family? How do we get along with each other? How do we feel about ourselves? What do we worry about? Take a survey (anonymous) on the concerns of the teenagers in the class.	Plan a week of "problem solving" programs which cover such concerns as: "making out" dating sex privacy parents independence curfew friends relatives school crowds food – diets "pimples"

B. Values

General – See *School Health Review* – February, 1974 – entire issue devoted to Values.

Values education consists of helping students become aware of their own values which serve as a basis for decisions, ranging in significance from a moral creed to live by to an influence on more mundane decisions. Provide for the continuing development of their own values or provide opportunities for their reinforcement.

Values teaching strategy should:

1. supply input about society's values
2. help students become aware of their own values
3. develop student's ability to recognize and examine the match or mismatch between his values and the values of others.

The aim of the values clarification approach is not to instill any particular set of values. The teacher respects the individual views and values of each student.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
B. Values **Objective:** Become aware of the basic values which guide your conduct. 1. During the teen years people develop values by which they guide their lives.	1. Invite your social studies teacher to discuss how people through the ages have dealt with the following questions: How did life start? Is everything an accident or a grand design? What do you mean by God? Why is there good and evil? Are right and wrong universal? Investigate and explain how holy books such as the Torah, Bible, and Koran served as a basic code of ethics for many people. 2. Explain why society adopts laws. Explain why people who regard themselves as ethical obey laws. 3. Discuss these 7 criteria for determining a value: CHOOSING: 1) freely 2) from alternatives 3) after careful consideration of the consequences of each alternative PRIZING: 4) cherishing, being happy, with the choice 5) willing to affirm the choice publicly ACTING: 6) doing something with the choice 7) repeatedly, in some pattern of life.	1. Make a large drawing. Picture yourself as a pebble dropped into water. The circles it causes represent people in your life. The first circle represents the most important person in your life, the next circle the rest of your family, the third your friends, the fourth your community, the fifth the world. Reflect on how many circles you include in applying your code of ethics. In what ways could you apply your ethical principles more widely? Are there any reasons why you should apply your ethical principles more widely? 2. Comment on the implication for your future if the following slogans were put into practice in your town: "The end justifies the means." "A master race would create a better world." "You have to crack a few eggs to make omelets."

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS

4. To acquaint you with the seven processes of valuing, appraise some of your beliefs or opinions to see if they are true values. After you have selected several health issues, privately examine your feelings about each one and list them on a valuing grid. The seven numbers heading the columns correspond with the following seven valuing questions.

1. Are you proud of your decision?
2. Would you publicly affirm it?
3. Did you consider alternatives?
4. Was this choice made after thoughtful consideration?
5. Did you choose it freely?
6. Have you acted on this choice?
7. Have you repeated this action?

If you can give a positive response to a question about a particular health issue, put a check in the appropriately numbered box. Leave other boxes blank. If all seven boxes have not been checked, you do not have a value about that health issue. After the grid has been filled out, be ready for a discussion.

Values Grid

Issues	1	2	3	4	5	6	7

4. To become aware that there are varying degrees of alternative choices between two divergent views:

Select a controversial health issue (e.g., legalization of marijuana). Place a horizontal line on the chalkboard or make a line on a sheet of paper. Write contrasting views of the issue at opposite ends of the line and a series of five equally spaced marks along the value continuum.

Legalize Marijuana ___/___/___/___/___ Do Not Legalize Marijuana

Indicate by a check where you stand on the value continuum line. After placing your mark on the continuum, express and defend your position. Follow this with a discussion.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
	5. List "20 Things I Love to Do." Save the list. Repeat in 3 weeks and compare them. Then check each one by asking: Do my life plans include time for activities I prize?	
	Make 10 statements about yourself that show what ideas, activities and/or possessions you value. Then examine each one to see if they fit the criteria for determining a value.	Ask yourself, and write an essay with the answer to: "Who Am I?"
	On a large card print IALAC (standing for I Am Lovable And Capable). Demonstrate to the class how your "sign" (feelings of being lovable and capable) was torn away piece by piece by a series of incidents on a "bad day." Then give each classmate a card with IALAC on it. Each time the teacher, classmate, parent, or a stranger says or does something to destroy their self-concept, let them demonstrate this by tearing off a piece of the card proportionate to the amount of damage. At the end of the week let each student show his card and tell what kinds of things destroyed it.	

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS

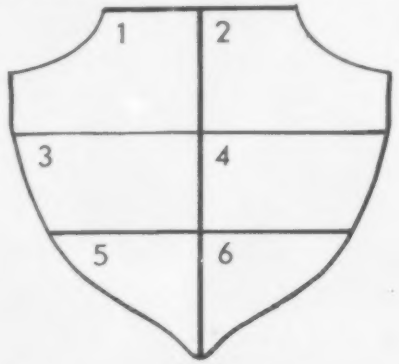
PERSONAL COAT OF ARMS
(Adapted by Kevin Lee)

Purpose of Activity

This activity provides you with an opportunity for internal reflection. As students continue to work with values-clarification activities, the following types of questions may arise: "Am I satisfied with my life and the goals I have set for myself? Are there changes I want to make in my life?" The personal coat of arms activity is a fun way for students to consider these questions.

Directions

Provide students with a full-page copy of the following coat of arms or let them draw their own:



Pictures representing student's answers to the following questions should be sketched in the appropriate areas of their coats of arms.

1. Draw a picture to represent one thing you do very well and one picture to represent something you are struggling to improve. This area will have two pictures.
2. Represent one value about which you have a deep commitment and would "never budge."

Values Level:

1. By using a line called a continuum, you are able to consider a particular issue and see where you stand in relation to others in the class. Claim your position on the continuum by placing a mark with your initials along the line. In order to delineate the limits of the continuum clearly and give all students plenty of room to find a position for themselves, make the end points impossible choices by giving them absurd qualities. In order to avoid some students taking a constant middle of the road position (often called the perch of the "compulsive moderate") you might remove the middle of the line, so students must make a choice.

How often do you get regular exercise?

Ron the Runner. Ron runs 24 hours a day, 7 days a week, 365 days a year. ..... Sitting Sam. Sam eats, sleeps, thinks travels in a sitting position; he never moves.

How often do you eat between meals?

Always. Never stop. I eat everything. ..... Never. Not even a piece of fruit.

2. Follow the continuum by asking clarifying questions such as:
   a. Are you as physically fit as you would like to be?
   b. What activities would you like to do better?
   c. If you have an uncomfortable feeling about your fitness, what are some things you can start to do in the next week?

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
	3. Draw the material possession most significant to you. 4. Draw two pictures in this area; one to represent your greatest achievement of the past year and the other to show your biggest setback, failure, or defeat. 5. Show what you would do with your life if you had one year to do whatever you wanted with guaranteed success. 6. What three descriptive words would you like people to write on your gravemarker. Emphasize that their drawings can be simple (stick figures, etc.) and need not have meaning to anyone but themselves. The coats of arms can be shared and discussed, if students choose to do so. From Values Clarification – School Health Review. Feb. 1974.	3. Autobiographical questionnaire. Construct questions about your classmates' lives that provide them with the opportunity to use the life skills of feeling, thinking, choosing, communicating, and acting. a. How do you feel after you have played for a long time? After you have rested after playing? When someone you like says that you are strong or trim? b. In the past, have you given much thought to the amount of food you eat, c the number of hours you sleep, or if you exercise regularly? Do you plan to think more about your health in the future? Why? Why not? c. Have you ever taught a friend a new game or skill; Have you ever had a classmate who was very overweight or not very well coordinated or didn't play games well? Did you do anything to help him? 4. Picture without a caption. Bring in pictures such as Mark Spitz at the Munich Olympics, an obese businessman sitting behind a desk smoking a cigarette, a boy and a girl hiking or riding a bike together. Have students write captions under the pictures. Their captions should express their feelings and values.

BACKGROUND INFORMATION 7-9

C. Realistic Goal-Planning

Milestones in Realistic Career Education and Goal-Planning

General –

By age 9:

understand the concept of work
appreciate the value of work
be familiar with a wide variety of kinds and fields of work

By age 12:

be familiar with the broad families of occupations
be aware of the prerequisites for employment in various kinds and fields of work
understand the ways of progressing from one occupation level to another
develop an awareness of his abilities, interests and aptitudes in relation to various occupations

By age 15:

be able to assess his own potential and to participate in making informed decisions regarding his immediate educational and occupational goals

By age 18:

be able to choose and plan the next step in his occupational and educational career.

Problems of Severely Physically Disabled in Attaining Vocational Goals:

1. Limited life experience
2. Doubts about future occupational status
3. Choosing a socially acceptable occupation without consideration of the child's interests and abilities may lead to continued failure and frustration
4. Students' over-dependency or unwillingness to accept help
5. There is sympathy for crippled children but relatively little for crippled adults
6. Students are conditioned to emotionally warm, comfortable environments and are psychologically unprepared for barriers which must be met without assistance

Suggestions to Teachers for Fulfilling Career Education Needs of Physically Disabled Students:

Insofar as emotional and social adjustment contributes to the ability of a disabled person to function in a social situation, it will also further his vocational growth.

1. Strengthen his adjustment to reality.
2. Foster the ability to compromise gracefully, to accept failure, and to continue striving.
3. Develop security to enable him to accept pressures and tensions incident to work.
4. Give him practice in how to behave properly at work.
5. Encourage attitudes and values which will motivate him to work. Make him willing to undergo discomfort to function productively.
6. Accustom him to routine, punctuality, and imposition of group standards.
7. Provide experience in facing problems.
8. Prepare him for employment in industry.
9. Encourage performance of chores.
10. Help the disabled child achieve a sense of the need and importance of accomplishment.
11. Provide a constant feeling of achievement in terms of work.
12. Set an attainable occupational goal and prepare him to reach it.
13. Teach him how to work, productive values, the sense of achievement, the willingness to accept society's standards, the emotional ability to postpone gratifications all as part of the process of work preparation.
14. Help him make a better vocational adjustment by strengthening those forces in his personality which enable him to value and accept other people and to achieve with them.
15. Teach him that he can accept himself and, by so doing, accept other people.

Information here was adapted from Seckendorf, Robert. "What Career Education Should Be." *Inside Education*. New York State Education Department, April, 1974.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
C. Realistic Goal-Planning **Objective:** Learn what tasks are involved in a profession or job you would like and investigate the personal abilities required for that job.		
1. An honest assessment of one's own abilities and interests is the first step in planning one's goals.	1. Ask your guidance counselor to give you a Strong Vocational Preference Test or a Kuder Thurstone Interest Schedule and then schedule a conference to discuss results in terms of your interests. Consult the SRA kit or a similar kit on careers.	1. Discuss how imagination and fear can each be a help and hindrance to you. List three realistic and three unrealistic goals for you, based on your special interests, talents, and limitations.
2. Learning about jobs or professions related to one's interests and abilities is another step in planning one's goals.	1. Explore occupations of interest by interviewing people working in the field, visiting different employment settings, inviting guest speakers who can tell about opportunities in the chosen field, viewing films about that field. 2. Through free association, produce ideas for products that need to be made.	1. Investigate job possibilities for you. List the kinds of jobs you could do. 2. Tell why each of the following is a realistic or unrealistic goal for you: Astronaut Trapeze Artist Costume designer or seamstress for circus performer

BACKGROUND INFORMATION 7-9

GOAL PLANNING FOR PHYSICALLY DISABLED STUDENTS

C. **Realistic Goal-Planning (cont'd.)**

What Parents should know:
Vocational choices start at infancy by contacts and by playing. One way of learning is role-playing different occupations. Confinement of disabled means that they don't go shopping, visit, work, do chores, mow lawns, etc. Parents must believe the child is employable. The child must contribute to the family. Parents must determine realistically what the child can do and give the child the opportunity to make decisions for dress, etc. Parents should talk about their jobs, involve the child in knowing about their work, let them visit them at work. The child needs motivation, self-responsibility, ability to make decisions. If the child has positive feelings about himself and is provided with real information about jobs he can make more realistic plans for the future. Hobbies should be varied. Explore interests and go on field trips. The school should include occupational guidance. Suggestions for preparing students: program of occupational samplers: tools, simulators, and materials of the trade.

What the Student Should Know about OVR:
Vocational Rehabilitation Program is a joint federal-state program for the handicapped. In New York State it is part of the State Ed Department. It was started in 1920. The Vocational Rehabilitation Act Amendment of 1973 – mandated to serve *severely* handicapped, and are cutting back on mildly disabled. The service program – designed to enable the handicapped to lead productive lives. Works with all community agencies.

How to receive service – anyone can refer a handicapped person, or an individual may apply himself. Eligibility – determined on the basis of current medical records. A person with a permanent significant emotional, mental, or physical disability which results in limitations and constitutes a substantial vocational handicap and who can have reasonable expectation of engaging in a remunerative employment after receiving services can get extended evaluations – OVR can place a handicapped person into experiences in the community to see if there is any chance for vocational rehabilitation. No age limit for anyone who wants to work. Kinds of services: will pay for general and special medical reports to establish eligibility; counseling and vocational guidance; may sponsor a college program; training – even for a sheltered program or a homebound program; part time homemakers; business, trade, on-the-job training, physical restoration services; special transportation to training site or college; adult driver ed program; reader services. Placement services – not too difficult if training is good and expectations are *realistic*.

Vocational Rehabilitation Amendments of 1974 were vetoed. Vocational Rehabilitation Act of 1973 – federal employers who employ in excess of 2,500 must employ and advance the handicapped in jobs without discriminating against them for being handicapped. There is a task force for affirmative action for employment of the handicapped.

Work in America provides status – tells person he is valuable – develops self-esteem.

Levels of Vocational Involvement:

1. Creative leisure – (some handicapped can't afford to give up their benefits by becoming fully employed because they still need medical benefits) – become involved in avocational interests.
2. Sheltered, non-competitive employment – Goodwill Industries and CP Workshops provide a small salary and socialization.
3. Competitive home-bound employment – because they can't get to work five days a week – but they can be fully employed. Home employment possibilities: telephone answering, sales, handling substitute teachers, insurance claims adjustors, etc.
4. Work demonstration centers, like Abilities, Inc. in Albertson, N.Y., to prove that severely handicapped can be employed competitively in clerical, managerial, technical and industrial skills.

1. **Dysautonomia** – Limitations on working conditions include working outdoors. When working indoors, such conditions as excessive humidity, dust, or sudden changes of temperature must be avoided. Any type of work which would require a great deal of coordination or manual dexterity might be difficult.

2. **Spina Bifida** – Limits will be imposed on career choice depending on the degree of mobility the student has. Use of a wheelchair will narrow job locations to those places free of architectural barriers.

3. **Muscular Dystrophy** – Many are unrealistic about careers, planning work that is physically impossible for them. Since they are very interested in sports they may want to be sports-casters. It is best to plan for the immediate future, that is, success in school and going to college. It is important that they be fulfilled now. They also need to have goals. Parents often have defeatist attitudes. It helps the student if parents can be helped to understand the importance of giving them a positive outlook. Research and medical advances

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
C. Realistic Goal-Planning (cont'd.) **Objective:** Plan realistic goals. There are realistic career plans for disabled students to be aware of.	1. View films such as: "Job Interview – Whom Would You Hire?" Film A – "Three Young Women" – 17 minutes. Film B – "Three Young Men" – 16 minutes. A Dimension Film distributed by Churchill Films 662 N. Robertson Los Angeles, California 2. Have a student volunteer to enact a job interview sitatuion. Then evaluate the job applicant on how he demonstrated the following important characteristics: Skills Reliability Attitudes Ability To Get Along Appearance Permanence 3. List and learn the meaning of 100 of the most frequently used terms on employment application forms. 4. Discuss the allegation that disabled people have to "prove themselves" in a job interview and on the job.	2. Review and discuss the following points to consider in going for a job interview. Dress – not extreme or too expensive Manners Attitude Neatness and Cleanliness Tell all the good things you can do Mention all your assets Good past record of time and attendance. 3. Practice filling out various kinds of job applications. 4. Prepare to look for work: Invite a special placement counselor of your state employment service to discuss how to prepare to look for a job including: working papers applying for a social security card filling out an application form writing a resume help from OVR

BACKGROUND INFORMATION 7-9

are constant. Conditions to be avoided: humidity, dust, sudden changes in temperature, outdoor jobs.

5. **Congential Amputee** – The unilateral below-knee amputee has minimal disability. If he has a well-fitted prosthesis, and has been properly trained in its use, he can do almost everything except for running.

The unilateral above-knee amputee cannot perform a job that will require carrying heavy objects and it must be understood that he will walk more slowly than a normal person.

The bilateral above-knee amputee has an extreme disability. He cannot be expected to stand for long periods or do much walking although he can stand for short periods and ambulate for short distances. He should be employed where he can sit down for most of the day or, if it is necessary to move, he can use a wheelchair.

The bilateral below-knee amputee can walk and stand well but he should be employed where he can be seated much of the day.

The arm amputee, whether bilateral or unilateral, above-elbow or below-elbow, also has special problems. He has no sense of touch in the terminal device and must look carefully at everything he does. Often arm amputees can work if changes are made in the equipment they use. This may require cooperation of the prosthetist, engineer, amputee, and employer.

7. **Achondroplasia** – When planning for a job the achondroplasic must consider extent and ease of commuting as well as physical requirements for a particular career. He will be limited by his size and degree of manual dexterity.

8. **Congenital Cardiac Condition** – Certain occupations may be dangerous – outdoors not too advisable. Indoors – an air conditioned area is best.

Limited range of career choices may cause frustration especially when children or their families are unrealistic about goals. Some have unrealistic career plans. Because of the tendency for this group to drop out of school, there is a need for early intervention, which includes scholastic remediation and extensive counseling for cardiac's family, as well as the cardiac himself.

One challenge for the rehabilitation worker is to aid the young cardiac to enter a 'proper' vocation – that is, one which is not only within his physical limitations, but which challenges *him* and will provide a good living. Don't sell him short by placing him in an overly restrictive environment.

Such counseling should be made available in setting where the youngster normally is found, i.e., school or medical clinic, so that it does not become an additional burden upon his limited physical condition to attend counseling sessions.

Safety of the public may restrict cardiacs from performing some types of work, such as, piloting airplanes. Commercial trucking is another inadvisable job.

9. **Hemophilia** – Vocational counseling plays a role in the school curriculum. It is especially important for hemophiliacs (indeed, for all handicapped persons) to face a prejudiced job market fully prepared – even overprepared – to compete for the job of their choice. Vocational counselors must be practical and realistic, guiding hemophiliacs toward areas where their services may be needed, yet avoiding occupations that demand excessive physical exertion or physical contact.

During a job interview, the hemophiliac may be torn about whether to tell about his disease while worrying about possible consequences in case of an injury. Teachers, parents, and friends know during childhood. As adults – others don't know about his disability and don't give him any special consideration.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
		Ask him to answer your questions about the current employment picture for disabled adults. Request booklets from the State Employment Office giving advice for job seekers.
	5. Interview your parents about the tasks they perform at their work. Ask about the satisfactions involved in their work. Make a list of the advantages and disadvantages of their job.	5. Combine lists with other students and compile your own class career booklet.
	8. Figure income taxes, learn how pay is computed, learn about proportion from a draftsman, architect or decorator, in math classes.	
	9. In social studies classes listen to a city planner describe problems of city building and decay or how local conditions affect employment opportunities.	
	10. In language arts prepare a resumé (curriculum vita).	
	11. Follow the day's temperature to learn about weather reporting or learn about construction jobs.	
	12. In a business class learn how to answer an ad to find a job.	
	13. Discuss what makes hobbies different from occupations.	
	14. Run a school store and school bank.	
	15. Concentrate on the different lines of work in a newspaper office and plant in putting out a school newspaper.	
	16. Discuss the work of the school custodian, maintenance man, and cafeteria workers.	
	17. Learn about food preparation careers such as caterer, chef, dietitian, short-order cook, baker, and food editor in home economics class.	

III. Dimensions of Maturity

A. Physical Maturity and Adolescent Development

General – A sex education curriculum which integrates knowledge of the reproductive system with an understanding of the responsibility, in our experience, can best be taught by coordinating related aspects of biology, social studies, language arts, home economics, psychology, and health education.

1. **Dysautonomia** – Help boys, whose growth is slow, to identify as males. Tendency to small stature (slower growth pattern) might cause difficulty in identifying. Anxiety about body image. Can't feel sexual sensation on external level. Male masturbation – lessened sensation of pleasure.

Puberty is commonly delayed in both males and females. About 50% of the girls will not have their menarche until over 16 years of age. Puberty does not have as dramatic an onset in the males as in the females but it is also delayed. There is fairly good correlation between physical appearance, bone age, and the onset of puberty. In those individuals who are extremely thin and small it is more likely that the bone age and puberty will be lagging. Puberty has not begun until 19 years of age in some individuals. However, primary and secondary sex characteristics eventually develop in both sexes. There is no indication at this time that reproductive functions are abnormal.

Adolescence is typically a time of stress and turbulence for any individual. The body is undergoing major hormonal changes and one is solidifying one's identity. If the parents encourage independence as much as possible, adolescent turbulence is somewhat lessened.

2. **Spina Bifida** – Girls born with spina bifida frequently start their menarche at a younger age, i.e., 8 or 9 years. An understanding of this development is unlikely until pre-adolescence. Reassurance that all is normal is essential. Physical assistance is necessary if the child is fully braced. Because there is a physiological change, the bowel and bladder program for the student may be disrupted and "accidents" may occur.

The boys develop normal secondary sex characteristics at the expected age. However, depending on the location of their spinal defect and nerve damage to the perineal region, not all boys are able to have an erection so the seminal

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
III. Dimensions of Maturity A. **Physical Maturity and Adolescent Development** **Objective**: Understand the wide variety of physical changes in adolescence. 1. Adolescence is a time of physical change leading to maturity.	1. Take a pre-test on your definitions of the following terms: a) chromosome b) ejaculation c) endocrines d) erection e) Fallopian tubes f) fertilization g) genes h) genitals i) hymen j) intercourse k) orgasm l) ovulation m) ovum n) semen o) seminal emission p) sex cell 2. View and discuss a film or filmstrip such as: Learning about Sex There's a New You Coming Becoming a Man Becoming a Woman Boy to Man Girl to Woman	1. After studying the correct definitions and reviewing them with your teacher, take a post-test on these terms. Ask your teacher to work with you while you check and correct your own answers.

emissions may not be present. The boys may feel "unmanly" because of the incontinence, especially if they are having to wear "diapers" and also have a flaccid penis.

3. **Muscular Dystrophy** – Body image is a particular problem to the MD adolescent. Increasing muscle weakness becomes more obvious, and wheelchair dependency, although resisted, becomes a necessity. While other children of this age are becoming more independent, the child with MD is becoming more dependent on others for all his needs. Because they are more immobile at this stage, the children become increasingly more uncomfortable while sitting in their wheelchairs. Pain occurs from pressure points, and frequent repositioning is necessary. The muscle tissue wastes away and the bones are more protruded. All the need for physical care makes maturation that much more difficult. When the adolescent with MD reaches the dependent stage, it is wise to encourage the use of a motorized wheelchair to allow for some independence.

5. **Congenital Amputee** – Disabled veterans may serve as a model of courage and accomplishment for those with congenital amputations. Physical maturation is usually "normal" for their age.

6. **Osteogenesis Imperfecta** – A poor body-image is possible because these children, especially the boys, tend to have small stature. Normal secondary sex characteristics do develop, but girls' menarche may be delayed.

Involvement in a more active physical life is feasible during adolescence because of a tendency to have fewer fractures. Boys can go into more aggressive sports programs. This will help their self-concept.

7. **Achondroplasia** – Because of size, they may act immature because they are treated as little children.

Peer relationships and self-confidence are upset in adolescence.

Usually independent in their ADLs. However, contending with an environment geared to the average size adolescent can cause frustrations. Provision for adjustments in the environment will help: e.g., step stools, lower lockers, etc.

9. **Hemophilia** – Develop normal male secondary sex characteristics.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
2. With the maturation of the reproductive system comes the ability to pass on hereditary characteristics.	1. Review the following laws which you study in science and tell how they apply to some trait that you have inherited: 1. Genes are responsible for inheriting traits. 2. Every trait has two genes. a. genes which are alike are *purebred.* b. genes which are different are *hybrid.* 3. Some traits will dominate others. A *recessive* trait is hidden by a *dominant* trait. This is known as the *Law of Dominance.* 4. Genes are segregated into gametes. (Pairs of genes are separated when eggs and sperms are formed.) Each gamete will receive one gene only. This is known as the *Law of Segregation.* 2. Invite the school physician to have rap sessions with students on "genetics" and "genetic counseling".	1. Study the following vocabulary of terms in heredity. Review them with your science or health teacher. Then make up a matching test of terms and definitions. Give it to a classmate while you take a classmate's test, and mark it. You should get at least 6 correct. If not, review, and repeat the test. **Pheno type** – appearance of the trait **Genotype** – actual genetic make-up **Homozygous** – genes which are alike (purebred) **Heterozygous** – genes which are different (hybrid) **Chromosomes** – carriers of genes **Meiosis** – reduction division which halves the pairs of genes. **Gamete** – egg or sperm cell. **Haploid** – half the normal number of chromosomes.

B. Emotional Maturity

1. Communicating

a. Asking and Refusing Help

General – Disabled young people must learn to ask for help and to accept it graciously. The way disabled present themselves to the world is the way people will accept them. Development of pride is needed. Well meaning people often give unnecessary and unwanted "help" in an effort to be kind. Coming up from behind and pushing a wheelchair when the disabled person does not expect it can be upsetting. Pushing a wheelchair over a curb the wrong way can cause a problem. Disabled students need assertiveness training until they can feel comfortable telling people to do or not to do some things for them. Let them act in progressively assertive situations to desensitize them.

b. Educating Others About Disability

1. Answering Questions Factually

General – Situations in which they are placed by peers and/or adults necessitate having a few pat answers from a young age. (I was born that way. Answer by asking a question – Why were you born with blue eyes?) Learn answers factually.

Need to cope with problem-solving approach rather than using defense mechanism.

2. Spina Bifida – Basic facts about SB include the physical defect in the spine and the resulting procedures to cope with paralysis. A SNT or physician could help students to formulate a clear simple explanation of the shunt, credé procedure, or Bricker device.

3. Muscular Dystrophy – The basic facts about Duchenne type of MD include a progressive weakening of the muscles of the body and the inevitability of an early death.

6. Osteogenesis Imperfecta – Students should stress that they are not "china dolls" though they may still be more fracture-prone than the average boy or girl of their age. Though a degree of caution is necessary even after the condition improves, older OI students can, with appropriate precautions, engage in many of the physical activities enjoyed by their able-bodied peers.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
B. Emotional Maturity		
1. Communicating –		
Objective: Take the initiative in communicating your needs and giving factual information about your disability.		
a. Asking and Refusing Help.		
1. Refusing and requesting help can be done in acceptable ways which promote good communication.	1. Role-play a scene in which you tell a friend not to give you help at that time.	1. Include some return gestures of friendship like a smile, a thank you, or a friendly remark about a mutual interest or a joke.
	2. Role-play the part of a non-disabled person who has just offered to give you some unsolicited help. Ask someone else to role-play your situation giving a friendly but firm refusal.	
b. Educating Others About Disability		
1. Answering questions about your disability in a factual way is a method of constructive communication.	1. Look up the basic facts about your disability. Look up and memorize a simple dictionary definition of your disability. Practice explaining both to another classmate and ask him to evaluate how clearly you explained it.	1. On a trip or when meeting a visitor to your school, or the next time a stranger asks you, explain your disability as intelligently as you can, keeping in mind that you may be regarded as a representative of the people with your disability.
2. You can "educate" the non-disabled about the abilities of the disabled through explanation and demonstration.	1. Interview (or read about) five successful people who are physically disabled. Find out what they can do best at work, hobbies, sports, etc. Make a list of the things you are best at or know the most about. Outline a plan for improving yourself even more in two of these areas.	1. Elect class representatives to act as tour guides for visitors. The tour guides should have monthly meetings to review the best ways to answer visitors' questions and to inform them about the accomplishments of the students.
	2. Publish a school magazine or newsletter about the accomplishments of your disabled schoolmates and about those of other disabled people.	2. Through your teacher, arrange to exchange letters with pen pals, informing them about the many varied activities and accomplishments of your disabled friends.

8. **Congenital Cardiac Conditions** – The cardiac can stress all the things about him that are the same as others his age, explaining areas where he must use maturity and caution regarding his health.

9. **Hemophilia** – Hemophiliac boys may question their future roles as parents and need information concerning the genetic aspects of the disability.

2. **Abilities of Disabled**

1. **Dysautonomia** – The child is often of at least normal intelligence and able to excel in hobbies like chess or bridge if he is emotionally suited to competitive games. Lack of co-ordination may hinder pursuit of certain hobbies, though interest may help to overcome physical limitations.

2. **Spina Bifida** – The accomplishments of Spina Bifida wheelchair basketball players can serve as a morale booster to young men. Strong uppers with good mobility will enable them to compete with a good chance of success in wheelchair sports.

3. **Muscular Dystrophy** – A motorized wheelchair will enable the student to move about with some degree of independence thus enabling him to maintain a better self-image as he interacts with the non-disabled.

7. **Achondroplasia** – The child has good mobility and can participate in many school activities where stature is not an important factor in performing. Success in such activities may help him to feel less "left out" of basketball, track, and similar sports.

8. **Congential Cardiac Conditions** – Sports will be one area in which the cardiac has little chance of success. He can, however, strive to excel in chess, bridge, chorus or other non-contact competitive pastimes.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
3. Taking the initiative in communicating with non-disabled people is one method of widening your circle of acquaintances.	1. Practice five ways of greeting a stranger or initiating a conversation. A) Ask a question which includes a positive comment about some asset of their school, (home, community, place of work, etc.). B) Ask directions and accept if they offer to guide you. On the way, ask question (A). C) Ask about their interests in teams, music, hobbies, and express yours. D. Discuss your goals in a positive way and ask about theirs. E) Offer to share information, ideas, a book, a map, a catalog, a record, etc.	1. Visit another school for a day and try out each of your methods of communication with a different student. In a round-table discussion later, share your evaluation of each method with the other students.

BACKGROUND INFORMATION 7-9

B. Emotional Maturity

2. Attitudes Toward Oneself and Others

General – Physically disabled have the same range of types and dispositions as physically able people. All people may be divided into the following four types

A. stars in every area
B. above average occasionally
C. average
D. below average achievers

If all four types have the same injury

A. becomes very depressed at the start and may fall apart completely
B&C. rehabilitate best
D. knows he can't make it anyway

Role of teachers and physicians in educating the disabled is to show them that they can achieve. Find what they can do and give them a feeling of achieving and and making realistic goals for them. Start at pre-school to plan realistic goals, don't overprotect. Let them realize there are failures and successes as part of living.

Other roles we (physicians and educators) have to play – need closer relationship with parents to help them to realize what a child can/can't do and to help them identify with their child. Children need advocate – someone who will speak for them. We must give them a feeling of *being someone*. Preparing for realistic goals on outside. Helping with opportunities to relate with children in other schools. Dances, basketball games, trips are good – More are needed.

Problems in classroom related to child's disability (or personality responses)

1. Dysautonomia – Teachers may encounter some difficulty in management of children with dysautonomia. The more involved his condition, the more difficult he will be to manage. They are aware of their problems: which may hinder their emotional growth as a person. There is no harm in giving them constructive criticism in class. In fact they need it. The children are looking for emotional controls. So be firm as is necessary. Complaints related to stomach distress can be due to an upsetting experience. In extreme cases the child may vomit.

There is a need for working together with their parents. They need to learn self-discipline as preparation for adolescence and adulthood.

Ambivalence concerning dependence vs. independence becomes intensified during adolescence, in a child with a chronic disease.

Body and emotional maturation are delayed mainly as a result of familial dysautonomia and also because of the strong parent-dependent relationships which develops. There may be problems such as non-acceptance by peer groups, withdrawal, anxiety (the child is often described as a worrier), and anger directed at a parent, or self.

The teenager should have outgrown the tendency to vomit when nervous or upset. Lack of control over his emotional reactions may cause anxiety when he is faced with new situations.

2. Spina Bifida – The goal of independence in toileting may be more important to the student's feelings of emotional maturity. Scheduled help with this physical problem can improve his emotional maturity. Unrealistic expectation, if given by parents, causes resentment. Parents sometimes promise them they will be "cured". Parents often unaware of sexual development of adolescent especially if they are in the habit of changing diapers. They do not consider the adolescent as maturing and accepting their growth is not easy. Children need guidance in selection of peers, as friends and dates. Children who have been isolated (or over-protected) as youngsters but are now growing away from parental guidance may seek friends who may not be the most desirable.

3. Muscular Dystrophy – Psychological aspect – he doesn't want to come to school, withdraws, does not do any work, acts very passive. The responsibility of the school is to attempt to maintain his self-image by putting him into situations in which he can achieve success.

Gradual transformation from being active and outgoing to the point of hostility and anger when they go into a wheelchair and withdrawal. Stress and frustrating situations magnify response and inability to hold back. They are seeing the transformation. Verbal mode becomes more meaningful. Re-

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
2. Attitudes Toward Oneself and Others **Objective:** Work to improve attitudes toward disability. 1. By learning to cope with disability-related problems realistically one grows in emotional maturity.	1. Discuss the following advice given by a successful disabled adult to a class of disabled high school students: a. Confront and accept your disability – Then others will also. b. You get rewards in life based on service not disability. c. Instead of acting hurt or angry, educate – Don't be "fresh" when people ask questions about your disability. Be able to discuss it calmly and coolly. – On occasion, let people help you. d. Use the questions and help as teaching experiences for non-disabled – Give them constructive exposure to the disabled. e. Find out what you can do. f. Get involved – You can do by doing – A healthy ego is important – take an active role. g. The disabled have a responsibility to change attitudes toward *them* for their own existence. h. Develop a rapport with people. i. Be open-minded but make your own decisions. j. Give yourself the chance to experience life. k. Don't be afraid to keep your goals, even if you must change your methods. l. Body-image makes the first impression but personality is what makes a relationship.	1. Read pamphlets or booklets such as "The Coping Books". Make reports and comment to the class on your reactions. Report form: Name _____ Class _____ Date _____ Title of Pamphlet _____ In general terms: What was the pamphlet about? What new thoughts has the pamphlet given you? How will these new thoughts affect your behavior?

BACKGROUND INFORMATION 7-9

sistance to the chair. Dependency on others for ADL's affects personality development. May become demanding, dominating, controlling, and manipulative. May try to control others for their own personal needs. Cause all kinds of problems in home by asking others to help them.

There may be a period of deep depression and withdrawal during the teen years as they go into a wheelchair and become increasingly dependent for ADL's. Deformities caused by weakening muscles can make them feel even more unattractive and many may avoid contact with peers because of their helplessness and appearance.

4. **Arthrogryposis** – Dependency. How can they cope with their dependency and still be a contributing member of the class? Must find their niche in contributing to the class. Maybe they can give in a verbal sense. They can be the listeners and thus important members of the group.

5. **Congenital Amputee** – Because of his appearance the congenitally deformed child may be rejected by his peers. He must learn to answer questions about the origin of his deformity and must cope with feelings of hostility toward the curious.

6. **Osteogenesis Imperfecta** – Students should dispel any unreasonable fears about their fragility, explaining how much their conditions have stabilized with maturity and just how careful they must be about broken bones.

7. **Achondroplasia** – Since he looks like a child, the adolescent is often treated as such. He must fight against the image of childishness that his small stature causes. With peers of normal size he may be painfully aware of his doll-like appearance.

8. **Congenital Cardiac Conditions** – The cardiac may look essentially normal and bring about no negative response to his "invisible" disability. His problems may arise from the limitations his condition places on physical exertion when interacting with more vigorous peers.

9. **Hemophilia** – The constant atmosphere of protection against dreaded bleeding episodes causes some young hemophiliacs to react by suicidal risk-taking while others become fearful and withdrawn, avoiding new activities. Able-bodied peers may fear social interaction with hemophiliacs.

2. **Attitudes**

General – Differences in self-description between children with and without handicaps reflect the functional restriction on physical activity, deprivation of social experience, and the psychological impact of the handicap.

Since it is easier to change attitudes before they have become crystallized, educators should consider integrated facilities in planning school construction for handicapped and non-handicapped children.

It is important to convey to people with disabilities, or to their families, that their lives can be rewarding, "that they can partake of life's meaningful offerings," that not all of life is disability-connected. Disability does not always comprise a hopeless struggle.

Even after an accidental injury, the person needs and wants help in realizing that the tragic impact will dissipate in time, that mourning is confined to a period of mourning and not a whole lifetime.

The handicapped person, in coming to accept his handicap, must become strong enough not only to see himself realistically but also to be able to avoid feeling squashed by the stereotype foisted on him by society.

He is likely to resent his fate – a resentment he directs toward people in general, even if they are trying to help him. It is not anyone's fault, for example, that he is blind, or that his life has been deprived in many ways; yet he cannot help feeling in some way that he has been cheated. No amount of kindness or help will make up for all he has been deprived of. Because much of his resentment will not be expressed, it will accumulate and result in feelings of guilt.

The child who feels that he is given treatment different from that of his brothers and sisters and is in some sense an outsider in the family, later will feel that he is an outsider in relation to the entire world.

The child will sense that there are areas of life which he cannot appreciate or enjoy. He will be aware that other members of the family take part in activities in the outside world which are shut off to him. The family may communicate a feeling of hopelessness which will be hard to remove. Paradoxically, the family may simultaneously communicate an opposite

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
2. Changing attitudes toward the physically disabled requires various experiences for the non-disabled as well as a great deal of patience and understanding on the part of the disabled. Some people may never change their attitudes.	1. Visit facilities where disabled people are in training programs, schools, rehabilitation centers. Follow up these visits with group discussion on what was seen and learned. 2. Discuss what disabilities are more repulsive than others, i.e., disabilities involving facial disfigurement are high on the list of rejections. 3. Invite a disabled adult to class and listen to his side of the story regarding how he was accepted as a youngster, what he has tried to do to change attitudes, what he would suggest be done to help change attitudes.	

attitude of unrealistic optimism or an excessive wish for the handicapped child to achieve independence – both of which can be obstacles to rehabilitation.

According to Beatrice Wright, there are several myths connected with attitudes toward disability. The myth of general maladjustment, the myth of tragedy, the myth of excessive frustration, and the myth of sin, are among the most disabling, not only to the person with a disability himself and those who are close to him, but also to the ordinary person, who, by them, becomes ill-prepared to meet the challenge of disability.

Modification of Attitudes:

1. The most effective is through intergroup contact or interaction.
2. Direct education programs are a second way of changing attitudes.
3. People who enjoy prestige in the eyes of the conformist can affect a change particularly if their statements are backed by action and not contradicted by other people of high prestige.

True acquaintance tends to lessen prejudice. Those who have closer contact preceive less difference than those who are farther away. On the other hand, casual contact may leave matters worse if participants are motivated to associate with the handicapped for such unrealistic reasons as sympathy or vague fears. Only the type of contact that leads people to do things together is likely to bring about positive results.

Legislation against discrimination is another possible device but is probably only indirectly effective in that it creates an atmosphere discouraging the development of practice of prejudice.

Psychotherapy is yet another way of affecting change in attitudes. While this is an important individual approach, it is not, at least currently, adaptable to large scale operations.

3. Making and Keeping Friends

General – Cruickshank (1952) found that social relationships do constitute a problem area for many crippled youngsters. In their desire to be treated as individuals, not as handicapped persons, these subjects wanted peers and adults to forget their disabilities but they lacked some of the social attributes necessary to bring this about. As a group they were less able than the non-disabled control subjects to evaluate interpersonal relationships. They tended to withdraw from social contacts, and they had fewer "normal" adolescent interests.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
3. Making and Keeping Friends **Objective:** Learn ways of making and keeping friends.		
1. Opportunities for making and keeping friends can be improved by: 1. Communicating effectively. 2. Developing one's assets. 3. Learning fundamental social behavior.	1. Talk about friends (school friends, camp friends, summer friends, best friends) and making friends. Ask questions: 1) What is a friend? 2) Why do we have friends? 3) How do we choose our friends? 4) Do we choose them on the basis of looks alone? 5) What do we expect from friends? 6) What is needed to be a friend?	1. Discuss reasons why the following traits handicap friendships: inconsiderateness, over-possessiveness, and insincerity.
	2. Discuss the advantages and disadvantages of friends who: 1. have different standards 2. try to control you 3. have doubtful reputations.	2. Take the Thurston Self-Evaluation Scale for Making and Keeping Friends.
2. Social maturity, personality, and qualities of character are often more important to friendship than physical appearance is.	1. Invite a psychologist to your health class to discuss manners and consideration for others as a means of overcoming a disability in social situations.	
	2. Plan an outline of positive steps toward better social acceptance for yourself.	2. Invite the psychologist to come back and discuss your success with the plan you've devised.

BACKGROUND INFORMATION 7-9

4. Accepting Responsibility

General – The school health project committee unanimously voted as a number one priority the need to develop the students' attitude toward taking responsibility in the following areas: In Student Council and Friday night recreation programs: planning programs, working out details and follow through for trips and weekly activities. Fulfilling assignments for classes. Taking tests or make-ups on time. Returning borrowed library materials on time, applying for college admissions tests on time. Based on this need, teachers, guidance counselor, coach, librarians, and club moderators made a concerted effort to involve students in participation activities and to expect students to be responsible for their own duties and assignments. The method adopted was to give instructions and set goals in small, attainable segments. One goal at a time was emphasized in each of the activities listed on the opposite page.

1. **Dysautonomia** – The fairly agile and able-bodied dysautonomic teenager could take part in volunteer activities involving both young children and the aged thus developing feelings of self-worth and value to others. Small stature and spinal deformity requiring back brace may affect body image, and feeling needed by another can help to boost his ego.

2. **Spina Bifida** – A victim who has persevered through therapy in order to walk will give encouragement to a younger child who is still working toward the goal of walking. The younger child may serve as a reminder of how far the older student has come through work in physical therapy. (This will apply only to those whose disability is not so severe as to eliminate the possibility of walking.)

3. **Muscular Dystrophy** – The telephone will serve as an aid to independent living for those teenagers who still have use of their arms.

6. **Osteogenesis Imperfecta** – Fragile bones often cause parental over-protection and infantile behavior on the part of children, who fear handling by strangers and may be unusually timid. Age should bring a lessening of dependence on parents as the physical condition improves.

7. **Achondroplasia** – Caring for a younger child can help the achondroplasic to feel like an adult rather than the baby he is often taken to be.

8. **Congenital Cardiac Conditions** – Service activities like volunteering to write letters for or read to the elderly can be a positive experience for the cardiac who can then act as the "strong one" for someone more feeble then he.

3. Reciprocal Benefit of Volunteer Activities

General – This kind of activity gives a reality experience. Practical experience in child observation and caring for the handicapped is especially important to those with hereditary defects who may have a handicapped child of their own. It gives students an understanding of the importance of early intervention to avoid deprivation retardation.

Language development would also be a mutual benefit. Younger students could learn by imitation. They would also find a need for clear communication. Consciousness of its importance could be a motivation for clear speech in the older helper.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
4. Accepting Responsibility **Objective:** Accept responsibility for your own care and school work.		
1. One develops independence by accepting opportunities for taking responsibility for your own physical care, mobility, and school work.	1. Plan your term's participation in one of the following activities that develop habits of responsibility: a) Helping others – Red Cross Club b) Working with others – Newspaper c) Involvement in planning – programs, trips, activities and follow-through committees for your class d) Explain to the class ways in which you demonstrate that you accept responsibility – for absence notes, homework, textbooks, library books, test-taking and make-ups.	
2. Accepting the responsibility for knowing where and how to get necessary health services will enable one to maintain health and relative independence.	1. List the hospitals and health service agencies in your area. 2. List and write to the voluntary and government agencies which supply information and help to people with your disability.	
3. Disabled people can contribute abilities and talents to the community.	1. Compile a list of agencies in your area which need volunteers and telephone or write to inquire about the kinds of volunteer tasks involved.	1. Arrange for a volunteer program in your school – perhaps for credit – for students to help either in primary classes or in a voluntary community agency.

BACKGROUND INFORMATION 7-9

IV. Interpersonal and Boy-Girl Relationships During Adolescence

General – Disabled young people need to be encouraged to participate in clubs and school group activities since they may be reticent about joining or worried about rejection. They must realize the benefits even of learning to handle rejection. Since opportunities for socialization at home may be impeded by problems of getting out to meet others, school-related activities are extremely important for them.

In the school, a small group discussion with the parents will help in their understanding of the development at this age of the adolescent. The parents of the handicapped student need to be aware that their adolescent is experiencing similar changes in his feelings and needs similar experiences in socialization with a peer group to help him learn something about interpersonal relationships, establishing friendships, and understanding the opposite sex.

Girls need encouragement to respond in feminine ways, and to present an attractive appearance, and to become interesting by developing a variety of hobbies or interests.

Boys need to identify with male models, to help with their manly development. Much of their life is spent in mother-related activities regarding physical care.

The teenager's disabilities do not permit him the freedom from supervision to join in the games and social activities of peers. Although the role models and expectations are there, they may be frustrated by the lack of opportunity for sociosexual growth in the socialization process. The handicapped teenager finds himself an onlooker to social, and particularly sexual, life.

They do have a deficit in sex knowledge when compared to other adolescents of the same age. A course in sex education can help to compensate for this lack of knowledge.

1. **Dysautonomia** – Encourage the adolescents if they are independent in ADLs to assume responsibility for their own care and selection of clothing. Becoming involved with this aspect will help them to feel in control of some aspects of their lives. Because these children often are immature for their age, encouraging involvement in self care will help them in maturation.

Often a Milwaukee Brace has to be worn for the scoliosis, so some advice regarding clothing may be helpful.

2. **Spina Bifida** – During adolescence they become more aware of the limitations imposed by their disabilities. Problems that have not been solved, become worse in adolescence. Advising appropriate appliances to handle the incontinence problem is surely more acceptable now because the students don't want to feel babyish any longer. Whatever can be done to help the students become more independent in self care will help their self image. Often during adolescence those students wearing braces will abandon them because they don't like their looks or the restrictions. Usually students who wear the double long leg braces with a Knight spinal attachment (over chest area) are not happy with this arrangement during adolescence and, depending upon how much influence their parents have and how physically independent the students are, will decide whether to wear them or not. Help the students realize why the bracing is important for their overall well-being and that during special events they could go without them but stress should be put on the value of wearing this appliance.

3. **Muscular Dystrophy** – It is difficult to improve one's self image when your physical condition is deteriorating right in front of your eyes. A lot of support and encouragement is needed. Help students develop a hobby so that there is a positive area they can be involved in and meet other people with the same interest.

4. **Arthrogryposis** – These students have difficulty sometimes in gaining a good self-image because of the limitations in their movements, frequent surgical procedures, etc. Lack of confidence may affect their ability to relate to their peers.

6. **Osteogenesis Imperfecta** – Small stature and timid behavior will often prevent these children from seeking new experiences or new friends. Feelings of inadequacy and fear of traumatic experience keep these children from

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
IV. Interpersonal and Boy-Girl Relationships During Adolescence **Objective:** During adolescence increase participation in activities which expand opportunities for interpersonal relationships. 1. Participation in school and group activities can expand opportunities for interpersonal relations.	1. Relate experiences with brothers, sisters, relatives, friends, and classmates which helped you learn to get along with others. After each experience draw a conclusion in the form of advice to your classmates. 2. Have a rap sessions with the school psychologist on developing relationships with the opposite sex and peers at this state in your growth and development. 3. Rate each other according to who you think is most popular in class and why. (or least popular and why) 4. Do a Sociogram and determine who relates to whom in the group. Does everyone participate in a discussion? Who talks with whom? Do boys and girls talk to the same or opposite sex? 5. Explore your community and determine what facilities (recreational) are accessible for a group, or inquire about using your school for a social event. 6. Develop 3 hobbies or leisure time activities which will help you to meet other people and bring students together in groups.	1. Have a member of a team, a band or choir, a club, a publication, or a hobby group each tell how belonging to the group helped them learn to get along with other teenagers. Invite a make-up or beauty consultant to class to demonstrate attractive make-up and discuss good grooming, etc. Invite a hair stylist to come to class and give haircuts or demonstrate new hairstyles which are easy to keep. Invite the school physician or school nurse-teacher to answer questions about acne and skin care. Invite the physical therapist to demonstrate body-building exercises to improve fitness in a way that makes the most of your abilities.

having good self-image. During adolescence their fragility improves, so slowly they can come out of their shell and learn to live more normal lives. Also, thoughts of heterosexual relationships are slow in developing.

Allow them as many experiences as possible to teach them to identify with males and females. Allow them heterosexual experiences. Encourage them to participate in many activities.

7. **Achondroplasia** – Clothing and cosmetics may make a dramatic difference in the age-appearance of a dwarfed person. Great lengths should be gone to to get the correct styles for the ages of the child. If sexual development is delayed, allow the girl to wear a padded bra.

8. **Congenital Cardiac Conditions** – If they have been overprotected as young children, it is difficult for these adolescents to feel free to pursue activities as they go all out in an attempt to prove to others that they are not restricted. Many are small as young children but average size by adolescence. Girls question ability to be mothers.

9. **Hemophilia** – Recurrent bleeding episodes may impede a normal maturing process. Overprotection as youngsters makes development of good self-image more difficult.

Mental Health & Family Life Education Module

Grades 10 - 12

Mental Health 10, 11, 12

Special Topics in this Module	Objectives
I. Personality Development	
A. Self-Concept and Emotional Health	Appreciate your abilities and accept your disabilities.
B. Motivation – Learning How Other Disabled People Succeeded	Learn about other disabled people who have succeeded.
C. Structured Leisure Time	Develop creative hobbies for using time enjoyably.
D. Death	Understand the customs and feelings people have related to death.
II. Sexuality	
A. Dating	Develop positive attitudes in coping with dating.
B. Problems of Sexual and Reproductive Ability	Understand your own sexual and reproductive ability.
C. Human Development and Disability Occurrence 1. Fetal Development and Disability Occurrence 2. Heredity – Its Influence on Certain Disabilities	Learn how disability can occur.
III. Family Life Education	
A. Understanding One's Parents	Understand your parents.
B. Preparing for Responsible Independence	Accept responsibility for caring for yourself.
C. Single or Married Adult Life	Appreciate your contribution to your future success as a single or married adult.
D. Experiences in Child Care	Learn to care for a child's needs and activities.

BACKGROUND INFORMATION 10–12

I. Personality Development

A. Self-Concept and Emotional Health

General – The general aim in developing self-concept at Human Resources School was one of "humanizing" in the sense defined by Ron Witort.

"Humanizing" as described by Ron Witort, University of Massachusetts, Workshop on Humanistic Education, 1972.

1. To accept a self-exploring environment in which there are no right or wrong answers.
2. To be aware of the many feelings each of us has.
3. To accept "ourselves" as worthy subject matter for investigation.
4. To develop and accept a supportive group atmosphere in our classrooms.
5. To experience new procedures for learning.
6. To know and accept the unique response each of us has to similar experiences.
7. To help students to describe themselves multi-dimensionally.

The steps taken at Human Resources School for helping the handicapped adolescent to build his self-concept include all the following activities and procedures:

Highly trained teachers using an individualized and enriched curriculum to compensate for absence and experience deprivation and provide more opportunities for achievement.

Training for overcoming architectural and attitudinal barriers.

Communication development through speech, dramatics, and social interaction projects.

Adapted health education program for coping with the activities of daily living and maintaining optimum health status.

The school health team worked with parents to broaden the students' success experiences in traveling to stores, churches, museums, libraries and recreation areas outside of the home and school.

Experiences added:

Wheelchair basketball team
Cheerleading squad
Pep rallies
Participation in Wheelchair Olympics
Studen*-faculty basketball and volleyball games
Musical and dramatic play presentations
Class trips to the State Capital to meet legislators
Trip to Philadelphia to Liberty Hall, etc. (each trip gave students an opportunity to spend several nights in motels, eat in restaurants, and cope with activities of daily living)
Recreational trips to Washington
Other trips: fishing, museums, major league baseball games, and cook-outs
Long Island Science Congress participation

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
I. Personality Development **A. Self-Concept and Emotional Health** **Objective:** Appreciate your abilities and accept your disabilities. 1. Appreciating your abilities and accepting your disabilities while trying new activities can help your self-concept.	1. In a log – 1) List all your abilities and assets. 2) List ten specific school achievements that gave you a feeling of success. 2. Form student groups to arrange as many of the following activities as possible: Wheelchair basketball team Cheerleading squad Student-faculty game Dramatic presentation Trip to a major league ballgame. A cook-out A fishing trip Participation in a local science fair or congress Class trip to the state capital to meet your legislators	1. Exchange ideas and advice with a friend about one other talent or area of study or ability you could develop in yourself. Share the best ideas with the class and develop a step-by-step plan for beginning to work on your self-development. 2. Discuss or write an essay, after considering which one of the following ideas about life expresses your thoughts: "It's what you are that counts." – Being thoughtful and loving, being dependable, being oneself, or being a person of integrity. "It's what you do that counts." – giving service or helping others, or being creative. "It's what you might yet become that counts." – engaging and becoming – growth is the key word; change toward greater knowledge, wider sensitivity, and broader capabilities gives added value to living.

The school also made arrangements to invite non-disabled students to our school functions and to create opportunities for our students to be invited to school functions at schools for non-disabled students.

Studies (Braun, 1975) show increasing evidence that "repeated success in school increases the probability that a child will gain a positive view of himself and high self-esteem. Repeated failure or low performance in school increases the probability that a child will develop a negative view of himself and low self-esteem."

The relationship between the child's expectations for failure in problem situations and withdrawal from such situations has also been indicated.

The perception of how well one is doing relative to others in the same situation appears to be the key link between school achievement and self-concept. The highest achieving students in a school with lower standardized test scores have a more positive view of themselves than the lowest achieving pupils.

High teacher expectations can have a positive effect on both the achievement and the self-concept of the students.

Cochrane (1972) reports that the physically handicapped adolescent's self-image is threatened by his physical lack of power, attractiveness, or competence which distort his perceptions. Recommended as helpful to the adolescent are the establishment of good relationships, the improvement of self-help skills, and the setting and reaching of goals.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
	3. Plan a schedule for your weekends in which you visit your local stores, library, church, museum, and recreation area, and report back to the class on the architectural barriers and accessibilities to each place. Compile a handbook of all the areas in which class members live.	3. Develop a student exchange-days program with a local high school. When the invited group spends the day at your school: 1. Plan for an orientation to the school. 2. Arrange to match "buddies" to be a guide for the day. 3. Invite the visitors to follow their buddy's program with them. 4. During free periods and lunch arrange a special program. 5. Have a rap session to share feeling at the end of the day and plan for the next exchange-day. 6. Follow-up with invitations to the exchange students to attend special evening events at your school, such as: a coffee house evening recreation a sports event a play production.
	4. Invite a club or group from another high school to a half-day workshop and a tour of your school conducted by your class. The workshop could explain how the disabled students overcome architectural and attitudinal barriers. The tour could be used to point out the activities and facilities referred to during the workshop.	

BACKGROUND INFORMATION 10–12

B. Motivation

The advice and reminiscences of two successful executives at Human Resources Center might serve as an example of the kind of information which could be shared with disabled students.

Richard M. Switzer is now Headmaster of Human Resources School and a success story. He is married and has five children, and is well known in the field of special education.

He was born with Cerebral Palsy. This means that the left side of his brain is damaged, affecting the right side of his body. Had a speech impairment. His right wrist is permanently bent-up so other children called him "mitty". Growing up he didn't know he was disabled. He still played ball, went to school. Looking back, he was the one they picked on, and wrestled to the ground. He laughed when they did. He was "one of the bunch" because he thought that they were laughing *with* him. On occasions he had operations on his right leg. When he went to the hospital he got gifts, kids visited, had breakfast in bed. He enjoyed it.

He had a cast up to his waist. Since there was no special busing in those days, his mother pulled him to school in a wagon. In elementary school, he didn't see himself as being crippled or disabled.

In high school he became conscious of his disability, and worried about the impression he made on girls, but he dated anyway. Some of the other boys played tricks on him, but he feels that he learned how to accept and cope with problems in adult life by coping with his friends' jokes.

His first time living away from home was his freshman year at Oswego College. The more homesick he felt the more determined he was to "stick it out." He wanted to be an industrial arts teacher but the college felt that a disabled person could not teach industrial arts.

At this time his family sent him to see Henry Viscardi, who was gaining a reputation for helping the disabled. He told Dick Switzer to fight for his rights and shared his dream of building a school for the disabled.

Mr. Switzer returned to Oswego and went into elementary education.

When he graduated from Oswego, he taught in Suffolk County in a brand-new program for CP children and soon became a coordinator of special education. During the summer he worked for Henry Viscardi in West Hempstead doing wire harness work with other disabled people.

Meanwhile he was dating his future wife, Pat, in Oswego, 450 miles away.

After he got married he went to Syracuse University during the summers to get his master's degree, and continued working in special education during the rest of the year.

In 1960, Henry Viscardi was starting his school, and called Dick Switzer to run its summer day-camp. From then on, he became the school's first teacher, and then its headmaster.

Advice to disabled young people:

One can have a job, marriage, etc. and still not be happy. You are going to school at least partly to prepare for a job. Your goal is to be happy most of the time. (If you are always unhappy, you have a problem).

If you are sitting home doing nothing you'll be unhappy.

His philosophy – work is good for you.

Show the boss you are willing to work extra time. You have one strike against you. To others you are different because you're disabled. You have to do a little more to make up for and prove you are better than non-disabled. Make them believe, until barriers go down. Show that you don't want pity. You want to be accepted on the basis of work.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
B. Motivation – Learning How Other Disabled People Succeeded **Objective:** Learn about other disabled people who have succeeded. Regardless of their physical disabilities, many people achieve their goals.	1. Invite as guest speakers successful alumni and other adults who are disabled and 1) ask them to tell how they succeeded. 2) Also ask them to tell about some discouraging moments. 3) Ask for any words of advice that might help you. 2. Read a book about physically disabled people who succeeded. You may choose from one of the books below, or one that your librarian recommends. This bibliography contains comments by physically disabled secondary students.	

BACKGROUND INFORMATION 10, 11, 12

Arthur Nierenberg is executive vice-president of Human Resources Center and president of Abilities Incorporated.

Since he had polio as a child, Arthur Nierenberg was on home instruction until his first year in high school. He would have given anything to go to school, because, for him, life started at three o'clock when his friends came home.

Since his friends were his brothers' friends, he did not know any disabled young people. There was no one who really understood his problems or could empathize with the embarrassment of being stared at or being asked the question, "How did you become 'crippled'?" As a matter of fact he had a "hang-up" about the word "crippled" and could not use the word himself for many years.

Because his father never said no he had a great many experiences often missed by disabled children. If he wanted to fish, his father would carry his wheelchair and him and and his equipment into the middle of a stream so that he could do it. One problem was that it was hard to find places to go to fish. Since he loved swimming, the family went often and carried him "piggyback" to the water. His father's belief in him became very important and his father's determination to help him to independence was the largest single factor in his success.

Notes on Reminiscences

Worries about how you look in a bathing suit. Is it worth exposing yourself to stares and exposures to curiosity? He looked around and saw lots of other people who didn't look so great.

Problems with new public situations – restaurants–waiters want to put you into a corner, they fuss with your chair, you have to manage accessibility to bathroom, etc.

Father's determination – Father made him practice over obstacle courses, etc.

Fear was a big part of life – when walking in crowds, on wet floors in bathrooms, slime on floors in cafeteria, food line. He played the violin – but couldn't carry it. If he had been allowed to use a wheelchair in school, a lot of fear and inconvenience could have been eliminated.

Didn't go out because of unwillingness to ask for help.

ADVICE TO OTHER DISABLED:

Open your mind – attitude is a very important factor.

Dating experiences – worried, uncomfortable, embarrassed, concerned with rejection. Confined to house – until he had a car. How would others feel? Not so different from natural hesitancy of adolescence. His own hang-ups spoiled dates – We often lose fun ourselves by worrying about others' reactions.

Any deficiency might be forgotten about if you forget it. But he never really thought that.

Don't accept that a disabled person can't do something.

Don't put fences around yourself.

Are we in control of the wheelchair and the disability? Don't let the disability tell you what you can or can't do.

Job interview fears are normal fears – Don't let the disability stop you from applying yourself.

New Law – Businesses are not allowed to discriminate against disabled as long as you can do the work.

Question – what do you tell them when you apply? Your own drive and confidence is the key to getting somewhere. Many think there are things they can't do – that they could do if they tried.

BIBLIOGRAPHY WITH COMMENTS OF PHYSICALLY DISABLED STUDENTS

Brown, Christy. *My Left Foot;* with a forward and epilogue by Dr. Collis. New York: Simon and Schuster, 1955. Reviewed by Peter Haughey and Nancy Naugles.

I think it showed that while a person with cerebral palsy may have difficulty controlling himself physically, he can use his brain just as efficiently as another person. It shows that disabled people can lead happy lives even though they may be limited in many ways in the physical sense. I feel that the experiences Christy Brown faced came across as something that is faced by many disabled people. Christy Brown faced many moments of uneasiness in his mind. Many times he felt depressed because of his disability. He also felt that he was in isolation from the rest of the world when he was left by himself.

Christy Brown is an autobiography which was originally called *My Left Foot* and now is called *The Story of Christy Brown.* . . . His mother taught him to write the alphabet with his left foot. His left foot was his only means of communication, except for different grunts and noises which only his family understood. . . . Christy Brown's life to come was not easy. He realized what pity was, what it was like to stay home day after day, he learned who his friends were and who came to see him just out of pity. Christy learned how to try to cope with all these things by writing and painting. . . . This book was one of the most interesting books I have ever read. I could relate with some of his experiences. I had and have some of the same hopes he had. It was very realistic. I learned a great deal from it and I think everyone should read it. It's a book I'll never forget and would read many times again.

Browning, Elizabeth. *I Can't See What Your Saying.* New York: Coward, McCann and Geoghehan, 1973. Review by Edward Zebliski.

This book is about an aphasic child and his mother's efforts to bring him to self-reliance. . . . The main thing I think a non-disabled person would learn is what aphasia is and what it can do to a person. I myself also learned what it is too. This book will prepare a non-disabled person for what to expect when he meets an aphasic child. He will know to have patience to hear what the child has to say and to speak slow and clear so the child will understand him. And he should learn to have no self-pity for the child. . . . It held my interest pretty well because it didn't describe every little detail and describes the technical things very well so that you can understand it. . . .

Chappell, Eleanor. *On the Shoulders of Giants; The Bea Wright Story,* with foreward by Basil O'Connor and Helen Hayes. Philadelphia: Chilton Co., Book Division, 1960. Reviewed by John Keelin.

This is the story of Bea Wright, a middle-aged woman who was working in Chicago during the time of the great Polio epidemic and contracted polio. . . . She could not, and would not let herself be in a wheelchair for the rest of her life. . . . From this story a non-handicapped person would learn that just because someone is in a wheelchair does not mean that this person cannot do ordinary activities such as going to the stores, going to dances or other social activities and even holding down a job.

Dishman, Pat. *Ten Who Overcame.* Nashville, Tennessee: Broadman Printing., 1966. Reviewed by Glen Searles.

I think the book *Ten Who Overcame* was very good and easy reading. The book showed the conflicts and hardships of ten people. It showed how they overcame their drawbacks and disabilities through an everlasting faith in God. I would say the book would be ideal for a non-disabled person. From this book they would learn that disabled people should be respected for their bravery instead of pitied. They would also learn that, like everyone else they have ambitions and goals that they set before themselves. . . . Some disabled persons might be able to identify with the book through similarities in desired vocations or disabilities. Yet some may identify with the characters' faith and trust in God and themselves. . . . I think it was good, the way the author wrote of a series of incidents with sectioned plots which I thought were very good. I also believe the ten characters of the book seemed very real and life-like. They seemed as if I knew them or perhaps I am them.

Ellis, Frank K. *No Man Walks Alone.* Westwood, N.J.: Fleming H. Revell Co., 1968. Reviewed by Gary Brendel.

The book I read, *No Man Walks Alone* by Frank K. Ellis, was about a United States Naval Officer who had both legs amputated when he crashed a jet. The book was an autobiography. A non-disabled person would most probably get the feeling that disabled persons learn to live with their disability and as in this case took up different techniques to do the things that he used to do. A disabled person might identify with the book in that this man, Frank Ellis, kept setting goals to reach and when he got to that goal he would set another. . . . The book might appeal to older people who have gone through most of their life and can identify with the things this guy writes about.

BIBLIOGRAPHY (continued)

Epstein, June. *Mermaid on Wheels: The Remarkable Story of Margaret Lester.* Sydney, Australia: Ure Smith, 1967. Reviewed by Regina M. Boutin.

I think that Margaret Lester's ambition and determination would be a great inspiration to the disabled person. I could identify with the story very well because Margaret experienced many set-backs in her rehabilitation, but always bounced back, as I feel I do.

Gunther, John. *Death Be Not Proud.* New York: Harper & Row, 1949. Reviewed by Megan McCaffrey.

Johnny Gunther was a 15-year-old boy with a brain tumor. When Johnny found out that he had a brain tumor, it was in the early 40's. Johnny was a very happy boy and was very intelligent. He enjoyed school and getting his high school diploma meant a lot to him. He was told to rest, but he was determined to get his high school diploma, and he got it. Johnny died a few weeks after his graduation. . . . The book would help a disabled person see that your disability should not stop you from doing what you want to in your life. A disabled person is capable of doing what any non-disabled person can. Only a disabled person has to do it in a different way.

Henrich, Edith and Kriegel, Leonard. *Experiments in Survival.* New York: 1961. Reviewed by Daniel Rodriguez.

Experiments in Survival described how a number of people coped with their disabilities. . . . To me the most interesting story was about Frank Gentile, who is now a Vice-President of Human Resources Research and Training Center. He got polio when he was sixteen and spent a long time in the hospital in an iron lung. He then spent the next year and a half working diligently to rebuild the muscles in his body. He later went to college and got an advanced degree in rehabilitation counseling. . . . We could all learn a lot from him. . . .

Massie, Robert and Suzanne. *Journey.* New York: Random House, 1975. Reviewed by Joseph Dowd.

Journey, written by Robert and Suzanne Massie is a detailed account of how hemophilia (the bleeder's disease) can affect the daily life of a family. Mr. and Mrs. Massie have a good vantage point from which to tell the story for they are parents of a hemophiliac.

Suzanne Massie narrates the day by day problems of hemophilia, giving the reader insight which no textbook could possibly provide. She writes of emotions which are difficult to deal with let alone describe in a book. Though Mrs. Massie has a tendency to dramatize her life she still portrays many aspects of life correctly.

Robert Massie, the author of *Nicholas and Alexandra,* writes mostly of the history of hemophilia and its treatment. At times he does descend from his academic throne to discuss the very human role he plays as father of a "bleeder," a very misunderstood role, I may add.

Reading *Journey* was not easy for me and it may not be easy for you. But if you put the time and effort into reading it you may find a new dimension to life.

McEldowney, Dennia. *The World Regained.* Boston: Beacon Printing, 1957. Reviewed by Michael Bernstein.

The World Regained is a story about a boy with a lot of problems. Bill the main character was born a blue baby. He had a very bad heart condition and at first couldn't walk. But he believed in himself and kept on trying until he was finally able to. . . . Disabled people can learn a lot from this book. They would learn the value of trying and of making the most of what they have. Persons with physical disability should develop the mind and concentrate on their attributes which are many.

Perkins, Faith. *My Fight With Arthritis.* New York: Random House, Inc., 1964. Reviewed by Marc Campbell.

Mrs. Faith Perkins is the author of her own book, *My Fight With Arthritis.* She herself had arthritis, and didn't even know it, until she went to a doctor, and he told her. . . . Any disabled person would be helped from reading this book. They would learn that they are not the only one with arthritis. And that in time they can overcome their illness. To me, Mrs. Perkins' book was true to life because I know what she went through and is still going through.

BIBLIOGRAPHY (continued)

Russell, Robert. *To Catch an Angel: Adventures in a World I Cannot See.* New York: Vanguard Printing, 1962. Reviewed by Roger Goun.

To Catch an Angel is the autobiography of a man who was blinded by an accident at the age of five. Despite this, he managed to achieve his B. Litt. from Oxford University, marry and raise a family. . . . Being disabled, I know what the author means when he tells of his fight for acceptance into a non-disabled world. But to a non-disabled person who may not have had much contact with the disabled, his story may seem ridiculous. . . . Call it inspiration if you will, but I really don't think a person can be inspired that way unless his heart was really in it beforehand anyway. It seems to me that anyone that this book gives "a new lease on life" to had it in him to begin with, but just needed something for reassurance before taking the first step. . . . He seems like he really means what he's saying, and I recommend that his story be read.

Stump, Al J. *Champions Against Odds.* Philadelphia: Macrea Smith Co., 1952. Reviewed by Fred Bachynsky.

. . . This book came across as true and sincere, because this is a book about real people in sports like Ralph Kiner, Mel Ott, Gil McDougald and Eddie LeBaron, etc. They are people who, despite their handicaps, became stars in their field of sports and who are still contributing in sports in some way.

Viscardi, Henry, Jr. *A Man's Stature,* introduction by Bernard M. Baruch. New York: John Day Co., 1952. Reviewed by Michael Polimeni.

. . . The book is written in a way that makes it simple to understand. This book does hold your interests by showing how a man against great odds overcame his disability. It also keeps your interest by his determination and courage to convince society that the handicapped are capable of holding jobs and making it in society. . . .

Viscardi, Henry, Jr. *The School.* New York: Paul S. Eriksson, 1964. Reviewed by Joseph Dowd.

The School by Dr. Henry Viscardi tells the story of the creation of Human Resources School. The book tells the story of how Dr. Viscardi, with the help of a number of dedicated people, opened a school for children who had no school. . . . The book is well written. It may not go down in history with *Hamlet* or *Othello* but is concise and right to the point. It even graphically describes disabled people with their physical as well as their emotional handicaps. . . . The plot was interesting to me as an almost historical work teaching me about my school's history. Other people may disagree but I found the plot very interesting.

BIBLIOGRAPHIES ABOUT HANDICAPPED PEOPLE

Moorachian, Rose, and Metcalf, Louisa S. *No Pity Please – Courageous People Face Their Disabilities.* Boston: Boston Public Library, 1967. (Available as a reprint from Easter Seal Society.)

The National Easter Seal Society for Crippled Children and Adults. *Selection of Recent Books about Handicapped Persons.* Chicago: Author, November 1973.

Teachers of the Visually Handicapped: Zita Auerbach, Caryl Chorlian, Else Feldheim, Edra Sachs. *Bibliotheraphy, An Annotated Bibliography Dealing with Physical and Self-Image Handicaps.* Jericho, New York: Nassau Board of Cooperative Educational Services, n.d.

BACKGROUND INFORMATION 10, 11, 12

C. Structured Leisure Time

General – There is a special need for developing hobbies and creative activities for those confined to the house. The disabled are often faced with the need to fill leisure time. To develop the habit and ability to structure their leisure time effectively, they need someone to show them how. Ideas aren't enough. They need group mini-sessions or workshops with definite results expected.

In addition to finding satisfying ways to fill their leisure time, they may discover a talent that they did not know they had.

Examples of Hobbies to be enjoyed from a wheelchair

Items To Make	Tools and Equipment Which May Be Utilized	Physical Requirements For The Craftsman
I. Needlepoint		
Fashion accessories, furniture pads and upholstery pieces, household pieces, household ornaments, rugs, pieces for framing or pillow tops.	**Hand Frame** – Held in one hand while the other manipulates thread. Portable and convenient for those with use of both arms. **Standing Frame** – Holds canvas stationary at wheelchair height, leaving both hands free to handle needle and yarn. Not portable like hand frame, but easier to use when arm mobility is limited.	Good vision and the ability to manipulate needle and yarn through the holes in a canvas. (**Quickpoint** is a form of needlepoint with larger mesh, canvas, needle and yarn; it will require the least acute vision and degree of manual dexterity).
II. Embroidery		
Decorative garments, fashion accessories, household ornaments, pieces for framing and pillow tops, decorative kitchen, bath, and bedroom linens.	**Hand Hoop** – Held in one hand while the other manipulates the needle and thread. Portable and convenient for those with use of both arms. **Standing Frame** – Holds cloth stationary at wheelchair height, leaving both hands free to handle needle and thread. Not portable like hand frame, but easier to use when arm mobility is limited.	Good vision and fine motor coordination necessary for splitting thread and threading a small needle. Stitches require more manual dexterity than needlepoint, and most of them will require the use of two hands. (**Crewel** is a form of embroidery that uses yarn instead of cotton thread, and will require the least acute vision and degree of manual dexterity).

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
C. Structured leisure time **Objective:** Develop creative hobbies for using time enjoyably. 1. Structured leisure time can fulfill a creative or practical need.	1. Conduct group mini-sessions in: 3-dimensional picture making weaving chess cosmetology needlepoint, embroidery, punch hooking personal typing communications – radio station public speaking Japanese paper folding brush stroke photography	1. Make a contract: "In _____ sessions I will make (or learn) the following three things: 1. _____ 2. _____ 3. _____

BACKGROUND INFORMATION 10, 11, 12

Examples of Hobbies to be enjoyed from a wheelchair (continued)

Items To Make	Tools and Equipment Which May be Utilized	Physical Requirements For The Craftsman
III. Punch Hooking		
Rugs, furniture pads, pieces for framing and pillow tops.	**Standing Frame** – Holds cloth taut, leaving both hands free to manipulate punch needle or shuttle hooker through cloth. (A lap frame can be used, but might be awkward for this craft, where the sharp needle punches down through cloth in an abrupt, hard motion. Such a frame would be appropriate only for small pieces of work which could be held away from the lap). **Punch Needle** – Worked with one hand, which guides yarn and gauges stitch length as it punches yarn through background cloth. Allows the person with strong grip and good mobility in one hand to guide stitches himself. **Shuttle Hooker** – Worked with two hands, which open and close shuttle in a scissor-like motion, merely guiding it as it punches even stitches through cloth. Requires two hands but less strength than punch needle and guides stitches for the user.	Fair vision and good use of one arm to thread and manipulate needle or hooker. Less fine motor coordination required than for embroidery or needlepoint, especially when shuttle hooker is used.

BACKGROUND INFORMATION 10, 11, 12

D. Death

Death Education Advice in Professional Literature

Nagy's study of the child's view of death found three stages: "Stage One: present until age five – death is understood as separation, as a state of being less alive. The child does not yet recognize that death involves complete cessation of life, nor is the finality (non-reversibility) comprehended. Stage Two: between the ages of five and nine – death is now understood as final. However, one might still be able to elude death; the inevitability and personal-reference components are not yet established. There is a strong tendency to personify death. One might be able to out-wit or out-luck The Death Man. State Three: from age 9 or 10. Death is both final and inevitable, 'like the withering of flowers'."[1]

The right time or "teachable moment" in the early grades often arises when a student mentions the topic or asks a question. They may be reassured that most people live to be older and that the death of a child is not a frequent occurrence. They can also be told that illness is not usually terminal.

Elizabeth Kubler-Ross supports the hypothesis that the real fear of death is fear of catastrophic, destructive forces bearing upon us against which we are powerless. Understanding this can help us understand the communications of children facing death. In addition to plain English, children may use symbolic non-verbal language, and symbolic verbal language to convey their needs and fears. When children describe a catastrophic or destructive force they may be trying to communicate about death.

For the child who cannot talk about it, asking him to draw a picture might give him a non-verbal opportunity to express himself.

Talking about other things might also help a child lead up to his thoughts about death.

There are several understandings that are needed by the teacher of a child who is dying or has a terminal disease like Muscular Dystrophy, (Duchenne).

In their sadness, family members will inevitably communicate their pain and grief to the dying youngster and often, in their anguish, they may withdraw from the dying child and become less available to him emotionally. Often the fatally ill youngster will also pull away from his mourning relatives because he realizes he is causing them pain and he does not wish to make them suffer. Mourning relatives may need support and encouragement to help them grieve together and to mourn with the dying child. This mourning grief, which otherwise could lead to withdrawal, isolation and loneliness, can open the way to greater sharing and mutual comforting – to a more meaningful understanding which helps the child and the family to live through this dying in a productive fashion.

As an inevitable part of normal mourning, people who care gradually withdraw their emotional investment in the child who is dying and reinvest in those people and those projects that will remain. This natural reinvestment allows the living to continue to grow. Sometimes the fatally ill child has not died by the time that he has been normally and naturally mourned. Advances in medical and surgical techniques allow fatally ill child to linger on and on. Family members may need support so they can continue meaningfully invested in this youngster who takes so long to die; often caring professionals may have to provide additional support to the youngster who has been too completely mourned. In the United States, families are often expected to continue a very heavy financial investment in the dying child during the very time that they are withdrawing their investment. These contradictory emotional processes may accentuate the family anger and anxiety, and the cost of the child's illness may become a prime focus for the family's mourning-anger.

Mothers whose children live longer than four months showed a calm acceptance of death when it came.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
D. Death **Objective:** Understand the customs and feelings people have related to death. 1. Understanding the customs and feelings people have relating to death can help one to discuss one's own feelings.	1. Discuss the reasons for the following customs which are observed when someone dies: Visiting the family of the one who has died, or sending a card or letter of condolence. Doing something to show we will remember the person – like contributing a book to the library, dedicating a yearbook or newspaper edition, planting a tree. Attending the funeral service or memorial service.	1. Discuss: Coping with realistic and unrealistic fears about dying.

BACKGROUND INFORMATION 10, 11, 12

First, it was found that the parents went through various stages toward adapting to the reality that their child was going to die. The stages approximated those that dying patients go through and were similar to the three stages of grief. Individual differences for coping developed and persisted, anticipatory mourning appeared, and as each child's illness entered the terminal phase, parents express mild resentment toward the medical staff. During the course of the child's illness parents seemed to use isolation of affect, denial, and motor activity as their main defense mechanisms; by the time death took their child the parents seemed calm, almost relieved to have the waiting period over. The anticipatory mourning was prominent and as time passed parents seemed more detached from their child. Evidence of restitutive efforts was suggested by the fact that several women became pregnant during or immediately after their child's fatal illness.

In some cases the strain of this condition does cause families previously in jeopardy to fragment and necessitates placement of the child outside the home. The effort to see the child through the terminal phase may also dissipate after the death and result in family breakup. The eventual increase in the child's need for medical care may also require placement near the terminal stage of the disease.

As in many chronic illnesses, parents tend to overprotect the child, for they are caught in a conflict between protecting the child and helping to motivate him toward continued growth or at least maintenance of growth (Tisza, 1962). Guilt seems to play a strong part for both parents because these conditions are generally recessive in nature; therefore, both parents have genetic responsibility.

Counseling with the parents is oriented toward the child's rights and needs, emphasizing the rewards to be obtained as well as their need to give to the child. The parents should also be encouraged to continue their personal development in areas other than those associated with child care.

The child with the terminal disease is often left out completely. He must receive help in understanding, as much as he is able, what is happening to him. There seems to be general disagreement among workers in the field about whether children should know what is going on. There is evidence that informing the child is very helpful and does not have great traumatic effects. In fact, sharing information with the child seems to improve his behavior.

Before they died, a number of the children in Schnell's study, despite their intellectual handicap, tried actively to help their families not feel so devastated about their impending death.

There have been observations of a tendency of dying children to manipulate their parents and to become excessively dependent. Guilt-ridden parents often over-respond unnecessarily to the child's slightest whim: waiting on him, dressing him, etc. What the child is usually saying is that he needs emotional support. However, oversolicitous behavior by the parents does not really satisfy such a need. Instead, parents who cater to the dying child frighten him more because they allow him to "die" as a person before his body succumbs to death.

To meet one's own death adequately is an outstanding developmental accomplishment; unresolved death is a tragedy. Death with resolution may not be a "loss". Loss occurs if the child and/or his parents find the challenge of death unmangeable and if the dying child's last days are spent in confusion, estrangement and sorrow. A wise point of view places much needed emphasis on the quality of life rather than its duration. This emphasis more than justifies the existence of psychologists on an oncologic team.

Contrary to initial expectations, members of families with a terminally ill child were in all major respects equally well-adapted as were family members in two other groups. No significant differences were found in anxiety, depression, guilt, length of future time perspective, or adjustment between the three groups of patients or between sibling groups, but mothers of the terminally ill children were more depressed than mothers in the other two groups. No clear relation was found between the family's degree of openness about the illness and the children's level of anxiety and depression. However, children from families which openly discussed the illness were less guilty than children from more closed families. Thus, families with a terminally ill child seemed remarkably well-adapted.

Information here was adapted from the following articles in the Summer 1974 issue of the **Journal of Clinical Physchology.**

Death Education for Children and Youth. Dan Leviton and Eileen Cleiman Forman, p. 8-10.

Childhood: The Kingdom Where Creatures Die. Robert Kastenbaum. p. 11-14.

BACKGROUND INFORMATION · 10, 11, 12

The Languages of Dying. Elizabeth Kubler-Ross. p. 22-24.

Management of the Dying Child. William M. Easson. p. 25-27.

The Families of Terminally Ill Children: Symptomatology and Management. Diane I. Willis. p. 32-34.

Helping Parents Cope with the Dying Child with a Genetic Disorder. Richard Schnell. p. 34-35.

An Emotional Support Program for Parents of Dying Children. Logan Wright. p. 37-38.

Research on Families of Terminally Ill Children: Problems and Reward. Andrea Farkas. p. 41-43.

D. Death Education Experiences at Human Resources School

General – Following the death of any Human Resources School student, the procedure has been to allow the students to "ventilate" their feelings, emphasize positive aspects of the departed student's life, and allay students' fears about the present. The approach to death education at HRS has been an individualized one with conferences with the physican and individual students, following general "rap" session with the physician, SNT, and class teacher involved with the group.

The importance of the quality of life is stressed. The fact that everyone dies is pointed out. Reassurance can be given to most of the students that they are not in danger of sudden death. Many of them, since they usually do not know what their classmates died of, think that this could happen to them too. They should know what their disability is and should be helped to understand that they can continue living a comparatively healthy life if they maintain their health status by following their physician's special advice and by following good health habits.

Students with Muscular Dystrophy (Duchenne) can be treated with a hopeful attitude toward the future. All can understand that, with antibiotics and modern medical techniques, there are many people with their disability who are living longer and more productive lives.

Advice given by Dr. Greenspan to HRS seniors following the death of a senior boy who had Muscular Dystrophy: Instead of looking at what he lost and what we lost – look at the happiness his fellow students gave him and that he gave them, the friendship and enjoyment. Remember the benefits and good times he had in coming here to school instead of sitting home alone.

3. **Muscular Dystrophy** – They see many peers with Muscular Dystrophy expire. Stress the quality of life style rather than quantity. (Many old people don't necessarily have happy lives just because they live longer.)

At beginning stages – there is denial by parents. Sometimes they shop among doctors. Enzyme study and muscle biopsy give a definite diagnosis. If the first doctor does this, then they accept the diagnosis.

There is resistance to group counseling. Dr. Greenspan tried parent groups. It's the type of problem that has no resolution. They can express and get out feelings but enthusiasm for discussion lessens because of lack of possible solutions. One way of considering this is that if the person doesn't have the power to promote change – leave him alone. In non-directive therapy – a person has power to provide solutions to his own problems. SOLUTIONS: Talk about the immediate situation as it comes up. Dr. Marie Meier, psychologist at HRS, feels that religion helps them to face the problem.

II. Sexuality

A. Dating

General – Rejection, which disabled young people often experience, may make them feel less worthwhile. They need a great deal of help to see that another's rejection does not prove that they are worthless. See Albert Ellis' **Guide to Rational Living.**

The handicapped person must be careful not to lay everything at the door of his disability. It is often noticeable that, if a relationship breaks up, he ascribes this to his physical misfortune, whereas the same reasons operate which separate non-handicapped couples.

Because of social inexperience, disabled adolescents sometimes place a wrong interpretation on the behavior of those around them, and so one sees young people becoming infatuated with their companions and attendants of the opposite sex, during rides, outings, excursions and holidays. The friendly behavior of others may be misinterpreted and the relationship may be deemed more serious than was intended. A strong desire for friends may cause this misunderstanding. The handicapped adolescent should be alerted to the possibility of this misunderstanding.

Logistics are a consideration in socializing with members of the opposite sex. There is an advantage to being able to manage the physical details like transportation, accessiblity, etc.

More opportunities for wider social contacts must be provided by the school and the parents and, eventually, must be initiated by the students themselves to offset the naivete which may have resulted from early sheltering and confinement to hospital or home because of their disabling condition.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
II. Sexuality		
A. Dating		
Objective: Develop positive attitudes in coping with dating.		
1. Attitudes		
1. Attitudes have an effect on the success of the physically disabled in socializing with the opposite sex.	1. With your counselor or health ed teacher have a series of rap sessions or discussions on: How do you feel when someone rejects your friendship? Refuses a date? Tells you he/she doesn't love you any more?	1. Discuss various ways of handling the feelings and the situations. Ask the psychologist to add his advice on each method of handling the feelings. Ask the psychologist to explain to you the 11 irrational ideas which we all must overcome in order to cope with emotional problems, especially idea number 6 which irrationally says that you are worthless if someone thinks you do not measure up to his standards. The answer to this irrational idea is that someone else's opinion does not make us either worthwhile or worthless. Because I exist as a human being, I am an individual person, not a standard to be measured against anyone else.
	2. Discuss the Pros and Cons of dating a non-disabled person, dating another disabled person. Include in your consideration: Involvement of parents in helping with dating. (Involvement in helping with living arrangements if disabled marry.)	
Coping with Dating Problems		
2. Logistics		
1. Resourcefulness in meeting others and in dating have an effect on the success of the physically disabled in socializing with the opposite sex.	1. Role-play Friend A and Friend B. Friend A asks advice about going on a date. How can I ask her? What should we do? What can we talk about? What should I wear? Friend B gives the advice and tries to help his friend make a decision.	1. Brainstorm with a group of your classmates to find and list all the places you can go and things you can do on a date.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
	2. Appoint a committee to look up and call public and private transportation companies to find realistic ways of getting there: Ask whether they carry wheelchairs, whether they will pick you up at your home, how much it costs, whether buses, trains, subways will allow wheelchairs and will wait while you board, and whether you are permitted to travel alone.	2. Have a group recorder write down all the ideas and hand out copies to the group. Brainstorm to figure out ways of getting to: local school athletic events, community or church dances or social events, youth organization meetings, visiting friends at their homes.
	3. Explore your own community for accessible recreational facilities, i.e., movies, bowling alleys, library, museums, etc.	3. Discuss your feeling about dating with your parents. Tell them how you feel. Enlist their aid in getting transportation.
	4. Prepare a booklet with as much information as possible on your communities' facilities which are accessible.	
	5. Plan how to cope with getting help with your appliances, i.e., wheelchair into car; wheelchair up theatre steps; etc.	

BACKGROUND INFORMATION 10, 11, 12

8. Problems of Sexual and Reproductive Ability

	Disability	Potency	Fertility – Child Bearing	Hereditary
1.	Dysautonomia	Yes, but immature physically until later teens.	Bearing a child is a great strain on a mother with dysautonomia.	Yes
2.	Spina Bifida	Females – yes. Males – some yes, some no.	**Females** – yes – probably a great strain on kidneys. **Males** – may not be fertile.	No, but some indications of greater chance of a second spinal-injured child in families already having one.
3.	Muscular Dystrophy (affects males)	**Males** – depending on progression of disease. Eventually muscles become too weak.	**Males** – yes – if potent, fertility would not be affected.	Yes.
4.	Arthrogryposis	Yes.	**Males** – yes. **Females** – would be a great stain.	Yes (?)
5.	Limb Amputees	Yes.	Yes.	No.
6.	Osteogenesis Imperfecta	Yes.	**Females** – Depending on severity. **Males** – Yes.	Yes.
7.	Achondroplasia	Yes.	**Males** – Yes. **Females** – probably couldn't bear a normal size child.	Yes (?)
8,	Congenital Cardiac Condition	Yes – depending on the severity of the condition.	**Males** – yes (?). **Females** – probably too much of a strain.	No.
9.	Hemophilia	Yes.	**Males** – yes. **Females** – yes – are usually only carriers and not affected by symptoms.	Yes.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
B. Problems of Sexual and Reproductive Ability		
Objective: Understand your own sexual and reproductive ability	1. Under the guidance of the SNT and/or your physician, do an independent study project to answer the following questions: Can I marry? Can I have children? Is my disability hereditary? Then discuss your individual questions with your physician and ask him about the medical advances which have improved or will improve your future.	
1. It is important to learn that there are methods of achieving sexual satisfaction which can be learned from your physician or a rehabilitation center, and there is information available for most sexual and reproductive problems.	2. After a group discussion, elect one student to list major areas of concern and interest. Invite experts who can conduct discussions on these areas. Have questions written anonymously on cards and answered by the expert immediately or at the following meeting.	2. Follow-up the discussions by choosing a project of personal interest and use such outside resources as newspapers, magazines, personal interviews with experts, letters of inquiry. Project may be presented as a taped interview, a photographic or diagrammatic presentation, or an oral or written report, a skit, a puppet show, a science demonstration or other innovative means of summarizing and sharing what you have learned.
	3. Find out about the nearby "Hotline" telephone service for answering questions on sex-related problems. See Beitler, Ken, ed. *National Directory of Hotlines, Switchboards and Related Services.* Write to The Exchange, 311 Cedar Avenue, South Minneapolis, Minnesota. Price $2.00.	3. Write to the Institute of Rehabilitation Medicine, 400 East 34 Street, New York, New York, to inquire about their Sexual Reassessment Workshops for Disabled Adults – which provides information and counseling for improving the sex lives of disabled adults.

BACKGROUND INFORMATION 10, 11, 12

B. Problems of Sexual and Reproductive Ability (cont'd.)

General – Since sexually related problems of the physically disabled include questions about masturbation, alternative methods of sexual satisfaction, potency, ability to bear children, ability to care for children, questions of inheritance of disease, there is a real need for appropriate information and advice. In addition to medical and psychological viewpoints, religious and moral viewpoints should be included or made available and the teacher should be able to guide his students to the appropriate sources of information.

As to the mechanics of sex, Dr. Greenspan informs our teachers that, "Where there is a will, there is a way." Students can be helped to understand that many adults with a variety of severe physical disabilities have successful, happy, satisfying marriages.

1. **Dysautonomia** – Pregnancy may cause problems because they don't put on weight easily. Anesthesia would be a problem. They now know how to anesthetize – but care must be taken. Labile blood pressure may be extreme during delivery. Pressure on the chest as the fetus rises – because little sacs in lungs collapse and they don't get as good ventilation of lungs. They are encouraging the use of a pressurized breathing therapy three times a day now to build up lung capacity. (They don't sigh or take deep breaths. They do yawn occasionally.)

Can have pleasure sensations from sex. Masturbation is excessive and prolonged. Masturbation is very common for sensorily deprived children and they are sensorily deprived in a manner of speaking. Set limits – encourage them to want privacy. Masturbation, a search for sensory gratification, may be more pronounced.

There is no reason to believe that there is any fertility problem or that sexual function is abnormal. Some of the women have inquired about contraceptives. No contraceptive is particularly recommended or contra-indicated. The complications seen with any method may also occur in the dysautonomic individual.

Pregnancy certainly is a time of increased stress and we know that stress is not handled well. The common occurrence of nausea and vomiting in a normal individual may be exaggerated in the dysautonomic woman. In addition, the enlarged uterus can cause respiratory problems. Thus without even going into the stress of delivery one can see that pregnancy may not be advisable. At the appropriate time, this should be explained.

2. **Spina Bifida** – Bowel and bladder functions are impaired in paraplegia, and controlling them is a part of rehabilitation that has a bearing on marriage. If the techniques are mastered, it may be possible to hold a job, support a family, and take part in social activities of family and friends. This mastery also makes it easier to avoid esthetic problems in marital intimacies. Such problems require loyal devotion and an extraordinarily mature and cooperative partnership; the disabled person does everything he possibly can for himself while the other willingly gives what help is needed.

New procedures for females – the intermittent self-catheterization technique has given them a whole new perspective toward developing a personal relationship with a male. It is possible to stay dry for longer periods of time and avoid the embarrassment of voiding during intercourse.

Technically speaking, a female paraplegic can have intercourse more easily than a male paraplegic, since she does not have to participate actively. Although some such women have no subjective feelings of orgasm, they are perfectly capable of satisfying their husbands. However, others have reported a feeling of sexual fulfillment in intercourse even when definite physical sensation is lacking. Some have been able to conceive and to bear healthy children.

According to reports, women with very severe athetoses (involuntary movements) and ataxias (disrupted balance) can be perfectly capable of intercourse. The sexual act is followed by total subjective relaxation, which can last up to a quarter of an hour.

Spinal cord damage is the principal physical cause of impairment of sexual function, but the nature of the impairment is not at all uniform. The location and extent of the damage as well as its effects on the total health of the person determine the degree to which he is still capable of functioning sexually.

BACKGROUND INFORMATION 10, 11, 12

Interest in the opposite sex is usually unaffected, and secondary sex characteristics – voice, changes in body form, and so on are normal. One study of several hundred paraplegic and quadriplegic men patients showed that, more often than has been realized, sexual functions remain active and that in a considerable number of cases it is possible for the paraplegic to develop a reasonably satisfactory sex life. Careful individual consideration should be given to this goal in rehabilitation.

Fertility of the completely paraplegic man is low. The contributory factors include decreased spermatogenesis, recurrent infection causing a decrease in semen and spermatogenesis, and failure to ejaculate. Only about 10% of patients have ejaculation, and this may not be consistent. Some experimental methods of obtaining sperm for artifical insemination are under investigation. The total fertility rate for paraplegic men is probably about 5 percent. In paraplegic women the situation is different. Ovarian function is not significantly affected by paraplegia, so oogenesis and ovulation occur as in normal women. Since intercourse is feasible for her, the paraplegic woman can conceive normally. She is also able to bear children.

During pregnancy, toxicity and pyelocystitis can occur more often. Consideration should be given to the fact that labor is often painless, and that consequently there may be a so-called 'silent partus', while premature births appear to occur more often too. Sometimes the mother is able to bear down, although there may also be difficulties in expulsion, due to spasms or cramps, in the set of muscles surrounding the pelvic outlet. Delivery by Caesarien section will only occasionally be necessary, since vacuum extraction will usually bring relief when expulsion is difficult for the reasons named. Lastly, post-partum prolaspe is more often observed in these women.

In the most severe cases, the entire lower body is paralyzed, the patient is incontinent (the sphincters are not working) and the man is completely impotent: an erection cannot be produced either by mental stimulation, or via the reflexes. These cases suffer retarded growth in the lower body.

Usually however, it is much less serious: the paralysis of the muscles in the buttocks and legs is not really complete, sensation is partially or wholly conserved; the sphincters can be controlled to a certain extent, or the urine may be collected in properly made urine bags (for men more easily than for women) and the excretion can be satisfactorily regulated by a regular procedure.

There is seldom a complete emission; usually the semen if found in the bladder after expulsion (retrospermi). Fatherhood is rare. The libido can vary from slight to normal. On a few occasions absence of libido and secondary sex characters such as beard growth and breaking of the voice have been observed. Motherhood is possible. The delivery is generally painless during labor. The abdominal muscles usually allow the mother to bear down. Artificial aids are quite often required. Prolapse is not infrequent after parturition. The kidneys and their ducts need special care during pregnancy.

Another gratification from sexual activity reported by many cord-injured men is simply pleasing one's partner. A substantial number of marriages between cord-injured men and their wives based on a sexual relationship consisting of deep love, affection, and understanding combined with only expressions of tenderness, have continued with a good relationship for more than a quarter century.

The endrocrinological reactions and contraceptive problems of disabled women must be investigated along with the incidence of various gynecologic problems: vaginitis for example. Management of bladder function to maintain the proper aethetics of sexual activity should be studied. Positional variations should be considered along with the reactivity of nongenital errogenous zones. The frequency and types of non-coital activity, the use of adaptive devices, and appropriate environmental modifications must be included in any thorough study of the subject.

There have been numerpus deliveries of normal children to paraplegic mothers. Recognition of the onset of labor is difficult, so hospital admission is usually planned for about the thirty-second week of pregnancy. The actual diagnosis of labor and its progress depend mostly on observation of cervical dilation. Uterine contractions and cervical dilation occur in spite of the spinal cord lesion. Despite the increased risks of urinary tract infection, premature or precipitious delivery, autonomic dysreflexia, decubiti and anemia, pregnancies usually eventuate in vaginal deliveries of healthy infants.

Love between men and women and the ability to respond sexually depend on many factors other than purely physical ones, whether the individual is paraplegic or not. But the paraplegic will need to understand his own particular responses, their nature, and their limitations.

BACKGROUND INFORMATION 10, 11, 12

Poliomyelitis – There is often a misunderstanding here. When a man's legs are paralyzed people think that he is impotent. Such is not the case in itself. Libido, erection, coitus, potency, and the possibility of pregnancy are unaffected. Neither the sensation nor the orgasm are altered except in very exceptional cases, where there are complications. The intellect is not impaired, but obviously there can be difficulties: such as a mechanical hindrance to coitus; the abdominal muscles or the pelvic muscles in women may be paralyzed, with consequences to pregnancy and childbearing, both of which are entirely possible.

The severely involved post-polio patient has normal sex impulses. If the arms are paralyzed, masturbation is impossible. Rehabilitation workers who associate with them often notice strong desires for sexual relief.

Hemiplegia – Difficulties can arise through:

- Impotence, oftentimes at the beginning, of a relationship but also later (psychological and/or physical)
- premature emission of semen (ejaculation precos)
- the 'impossible' posture due to the unilateral nature of the paralysis
- the emotional reactions of the paralyzed person (and also indeed of the partner)
- the incontinence which sometimes exists (above all in women)
- the heightened reflexes and occasional contractures on the paralyzed side
- the aversion felt by the partner for the distorted body
- the noticeable difficulties in communication attending right-sided hemiplegia owing to speech disturbances (aphasia); coitus is then often used as a means of communication or 'communing'.

People suffering from hemiplegia can become fathers and mothers. There are no hormone imbalances, nor faults in spermatogenesis.

3. Muscular Dystrophy

Although atrophy of the testes and slight hormonal disturbances often appear, it is known that many sufferers can achieve a normal sex life. The muscular weakness, the contractures, the scoliosis, and the heart weakness can be inhibiting factors. Similar considerations apply to pregnancy and childbearing.

In the sufferer from progressive muscular dystrophy another picture is presented. After being initially healthy, the child gradually relapses completely. Sometimes, at puberty, an urgent desire for sexual experience is displayed, as long as it remains possible.

Pregnancy can impose a heavy strain when the muscular weakness is great, and where there is abnormal lordosis and malformed feet. Childbearing may have to be artificially assisted at delivery owing to poor muscular action. The function of the heart requires careful watching, and is sometimes a contraindication for pregnancy.

4. Arthrogryposis – Persons who by reason of a distorted or rigid joint have difficulty in finding a suitable position for intercourse are advised to study the literature in the subject, to find a suitable answer.

Rheumatoid Arthritis – This is a chronic inflammation, which attacks many joints in a gradual manner, especially the small joints of the hands and feet. At a certain stage, the large joints can also become involved. The specific sexual functions are not affected (this disease will often improve during pregnancy), but there are certainly difficult and restricting factors which can impinge on the sex life in an unfavorable way.

- the pain can be a serious limitation. The husband will be afraid of hurting his wife, and the wife can really be terrified of the pain during intercourse or may perhaps use pain as a pretext for avoiding it. Similar considerations apply to the husband. Certain medications may be recommended by your physician to relieve the pain.
- contractures, and locked joints can inhibit coitus both in men and women.
- serious disablements of the hands can create difficulties in coitus and masturbation.
- the prolonged suffering, the financial sacrifices, and the gradual disfigurement can impose a heavy strain on the marriage and lead to estrangement.
- the frame of mind of patients with rheumatoid arthritis is often cheerful, a particular brand of grim humor. However, there are exceptions to this rule.
- in one form of this disease, the mucous membranes are dry and vulnerable; and therefore also the vagina (Sogren's disease) causing an effect on sexual relationships.

BACKGROUND INFORMATION 10, 11, 12

5. **Congenital Amputee** – Poor body image often accompanies lack of a limb.

Although a disability may impose alterations in sex acts, sex drive and sexuality remain intact.

The mechanics of body position during sex play and intercourse might present difficulties. Balance, movement or lack of either may be a problem. Some problems can be solved simply, for example by suggesting to the upper extremity amputee to switch sides of the bed with the partner so that they have their normal arm free in the sidelying position. Change of position during sex might be necessary. In some cases, change from the male superior to the female superior position might be indicated.

Although prosthetics may be a nuisance, it will enable them to function more normally and capably and would help body image.

6. **Osteogenesis Imperfecta** – Normal development of sex characteristics although with the more severely involved OI's they may have a delay in the maturation process. The sex drive is normal.

If the adolescent is not severely involved then normal sexual relations are possible. The more fragile adolescent should seek medical advice prior to marriage. Because this is a congenital condition, genetic counseling is strongly advised.

Frustrations may be more related to finding a partner who might want to marry them.

7. **Achondroplasia** – 50–50 chance of having a child with achondroplasia – if they marry a normal partner.

It is possible for a dwarf to have sexual intercourse with a person of average height or taller, but it is unusual for two persons of such great disparity in stature to marry. All dwarfs are capable of having sexual intercourse and a regular sex life, irrespective of whether in teenage they require treatment with sex hormones or not and irrespective of whether they are fertile or not.

Many dwarfs are able to have children who may or may not themselves be dwarts.

8. **Congenital Cardiac Conditions** – Normal sexual development during adolescence in boys and girls. Medical advice is recommended regarding parenting.

Under certain circumstances, if the heart condition is compensated, there is no need to restrict the sex life. It may be surmised that coitus places a strain on a man similar to the ascent of a single flight of stairs which are not too steep. If this degree of effort cannot be tolerated then coitus has to be abandoned or ways must be found of taking it at a quieter pace or else this is not altogether without danger. Certain postural modifications may be necessary to perform coitus with a minimal effort.

(See Sex Education Bibliography in Appendix for sources of information)

C. Human Development and Disability Occurrence

General – From the 28th to 35th day (4th week) of pregnancy the occurrence of a viral infection in the mother could produce a brain damaged body. Up to the 38th day; if the fetus has been injured, a spontaneous abortion could occur. At this time Spina Bifida or Cleft Palate may develop. If there is an infection, i.e., Rubella (German Measles) at this time, the baby may be born with defective hearing, vision, heart and 8th nerve involvement. By the 38th day the heart, foregut and mesonephric ridge have started to develop. By the 43rd day the arm buds are begun. The leg buds, ventricle, liver, thyroid and lung buds are begun. The leg buds, fingers, arms and bone tissue usually start by the 51st day. If they stop growing, the baby is born without limbs or may have syndactylism which is a fusion or webbing of fingers or toes. By seven weeks the fetus is 2.25 centimeters or 1 inch in length. By 12 weeks the fetus has all limbs. All fetuses are female until differentiation occurs.

Usually the mother will feel movement of the fetus (kicking) between the 4th and 5th months. If the fetus has less movement than is expected there is serious concern about the condition of the fetus.

Disabilities resulting from birth defects would include:

Spina Bifida
Limb Deformities
Amyotonia
Hemophilia
Arthrogryposis
Charcot-Marie-Tooth Disease
Icthyosis
Amputee
Muscular Dystrophy
Heart Disease
Dysautonomia
Osteogenesis Imperfecta
Rubella Syndrome
Metabolism Disorders

2. Spina Bifida – Spina Bifida Manifesta can be seen at birth. Spina Bifida Cystica appears like a cyst on the spine – nerves and vessels are present in the cyst. The neurosurgeons and plastic surgeons have to decide what to do. Usually surgery is done right away. The sac (cyst) is opened and the nerve tissue is preserved if possible, and returned through the opening and covered with skin. Usually 90% will be educable. The average IQ may be slightly lower than 100 but many have high IQ.

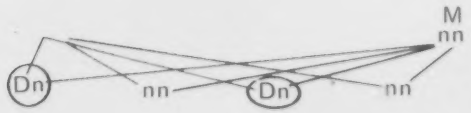
CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
C. Human Development and Disability Occurrence **Objective:** Learn how disability can occur. 1. Fetal Development and Disability Occurrence 1. It is important to understand the factors which influence fetal development and the etiology of defects.	1. Invite a pediatrician to discuss fetal development, determine at what stage the major systems are begun, and realize that this is when many of the defects occur. Discuss the importance of infection in the mother and the dangers to the fetus. Ask him to explain the significance of infection in the pregnant woman and the dangers to the fetus. 2. Discuss nutrition and pregnancy. 3. Discuss drugs and pregnancy as they relate to occurrence of fetal defects.	1. Choose student committees to follow the discussion with research reports on: Congenital disorders, Inherent or familial disorders, Causative factors affecting fetus and placenta. Abortions and miscarriages: legal aspects and ethical aspects. Follow each presentation with questions and answers which may be taped.

BACKGROUND INFORMATION 10, 11, 12

Heredity – Its Influence on Certain Disabilities

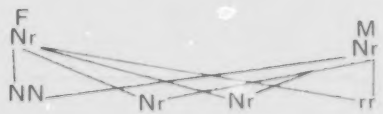
Dominant Inheritance: An affected child must have one parent with the same disorder. There is a 50% risk that each child will manifest the defect, though it may not be evident at birth.

Physical Disabilities:
Achondroplasia



Recessive Inheritance: Both parents of an affected child appear essentially normal, but by chance, both carry the same harmful gene although neither may be aware of it. Each child will run a 25% risk of manifesting that genetic disease. Each child will also have a 25% chance of not inheriting the gene from either parent; and each has a 50/50 chance of receiving only a single defective gene and becoming a carrier of the genetic trait like both parents.

Physical Disabilities:
Sickle Cell Disease
Thalessemia



X-linked inheritance (sometimes called sex-linked): Normal females have two X-chromosomes; normal males have one X and one Y. The most common X-linked abnormalities occur when the mother carries a faulty gene on one of her X-chromosomes. In such a case, each son has a 50/50 risk of inheriting that gene and manifesting the disorder. Each daughter has an equal chance of being a carrier like her mother, usually unaffected by the disease, but capable of transmitting it to her sons.

Physical Disabilities:
Muscular Dystrophy - Duchenne type
Hemophilia
Spinal ataxia (some forms)

Multifactorial Inheritance: A large group of genetic disorders result from the interaction of many genes with other genes or with environmental factors. The pattern of transmission in this group is less well defined but it is well known that the probability of recurrence is reasonably low. With one effected child in the family, chances of another having the same defect are 5% or less.

Physical Disabilities:
Spina Bifida Manifesta
Hydrocephalus with Spina Bifida
Cleft palate and hare lip

2. **Spina Bifida** – There are methods for detection of babies with neural tube defects. The most commonly used method of detection for "high risk" mothers is called Amniocentesis. Other methods are being developed to view the fetus in utero. However at this time these methods are not available for use with the general public. Many researchers are using these methods in the laboratory with good results. The nearest Birth Defects Clinic can provide all the necessary information regarding Genetic Counseling.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
2. Heredity – Its Influence on Certain Disabilities. 2. Heredity is a factor in certain disabilities.	1. Ask your biology or science teacher to explain the types of hereditary transmission of disability: **Autosomal dominant** – a dominant gene occurs on either the X or Y chromosome. **Autosomal recessive** – a recessive gene occurs on either the X or Y chromosome. **Sex-linked recessive** – a recessive gene occurs only on the X chromosome – which has no counteracting allele. **Polymeric** – a character dependent on several allele pairs.	1. Investigate the answer to: Can the incidence of the major types of congenital anomalies be reduced? If your disability is hereditary, ask your physician to explain genetic counseling and provide you with the name of a center for genetic counseling for future reference.
	2. Ask your social studies teacher about the transmission of hemophilia to many of the royal families of Europe. Read *Nicholas and Alexandra* by Robert Massie and ask your English teacher to discuss the part played by hereditary hemophilia in the destiny of the Russian Czar's family.	2. For an understanding of modern methods of coping and living with Hemophilia, read *Journey* by Robert and Suzanne Massie.
	3. What are some legal and moral questions involved with genetic counseling, and "human engineering"? Where are genetic counseling services available? (contact the National Foundation)	3. View the motion picture "Mystery of Life, the 21st Century," on genetic engineering and discuss the implications for persons with disabilities. Film available from: Film Rental Center, Syracuse University, 1455 E. Colvin Street, Syracuse, New York 13210.
	4. Visit a Birth Defect Treatment Center of the National Foundation–March of Dimes. Assess the problems involved in caring for a child with congenital problems.	4. Discuss the ramifications of the problems of who defines a disability, what constitutes desirable hereditary characteristics. Tell how this could be used as a political tool.

BACKGROUND INFORMATION 10, 11, 12

III. Family Life Education

A. Understanding One's Parents

General – The physically disabled adolescent views his parents with all the normal gripes teenagers have about the "older generation" but often not as aggressively because he is not in control of the situation. While most teenagers are moving through adolescence and moving away from parental influence toward independence, a physically disabled student, dependent in many areas of the ADL's, cannot make this natural break.

A natural frustration develops about their plight and some forms of behavior are seen which may not be socially acceptable.

A balanced prespective may be struck if the person can be helped to view his parents more objectively. Help students to understand that parents are reacting like normal individuals, perhaps to an increased degree because of their anxiety about their child's physical condition.

Parents reactions to their disabled baby:

1. Mother's first reaction is that it is her fault
2. Father feels it is his fault, or he may blame wife vicariously
3. Father feels hurt and disappointed, especially if it is a male child.
4. Mother feels inadequate – she disappointed her husband, family, parents, etc.

Important influences on parents' emotional well-being: how the parents were told that their baby was not 100% normal, who did the telling, what actually was said, and how the husband and family reacted.

Each physician handles a crisis the best way he knows how, and immediate referral to another professional expert to assist in this crisis situation may be the best way of handling the situation. Parents become frightened when an unknown situation is thrust upon them. They handle this emotion in many ways. Denial is often the first emotion. Other emotions similar to a "grief reaction" follow.

As the children grow, economic stress and strains add to the family burdens.

One way of helping parents is to encourage lines of communication between children and parents, parent and parent, and parents and teachers. The school can provide a setting for group meetings with parents to allow discussion of pertinent topics, sharing of information and ways of handling situations related to this age group.

It is possible to assist parents in their roles by sharing experiences with other parents who have similar problems. Many parents of disabled children feel very much alone and isolated. After a meeting with other parents, their problems seem solvable, or at least manageable in part. The burden seems less when shared with others.

Parents' meetings and discussion could be based on *Even Love is Not Enough, Children with Handicaps,* Parents' Magazine's Special Education Sound and Color Filmstrips: Physical Disabilities – 5 color filmstrips – 12 LP record or 3 cassettes, discussion guide, and 5 audio script booklets. Series consists of 4 separate filmstrip sets: Behavioral and Emotional Disabilities, Physical Disabilities, Intellectual Disabilities, and Educational and Language Disabilities. Physical Disabilities: (1) 3 Different Kinds, (2) Special Problems, (3) What Can We Do?, (4) Diagnosis and Treatment, and (5) Support Services. Produced by Parents' Magazine Film, Inc.

Isabel Robinault, in "Feedback from the Family of Man," *Rehabilitation Literature,* August 1968, makes several pertinent observations of parental need on the basis of letters from parents of disabled children.

273

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
III. Family Life Education A. Understanding One's Parents **Objective:** Understand your parents. 1. As they reach adulthood, young people often understand and appreciate their parents more.	List 10 things your parents do for you daily. List 5 problems your parents helped you to overcome. List 5 problems your parents have faced. List 5 worries that they have about you. List 5 things you do for your parents that you think are important. List 5 things you do for your parents that they think are important.	List 5 statements on the topic "My Parents Don't Understand Me." Then role-play the part of your mother or father while someone plays your part and reads your statements aloud. Answer each of your statements from your parents' point of view. Take 4 examples of family conflicts and describe how problem-solving procedures would solve them.

BACKGROUND INFORMATION 10, 11, 12

The earliest help for any child's development is attained by tossing a lifeline to his parents. Now HOW the lifeline is tossed is all-important. Most parents never receive it prior to crisis time, and unfortunately it often is a clumsy toss that aims at an isolated problem and offers no carryover. To be effective a lifeline should be curved toward Appropriate Guidance. Appropriate Guidance has two parts: Contained Counseling, which helps parents to manage (if not fully understand) their feelings, and Supportive Services, which help parents to act constructively on behalf of the total family, which includes the child who varies in some way from normal or from average expectations.

Parents of disabled children have problems of 1) Information Breakdown, 2) Alienation, and 3) Persistent Uncertainty.

In our Land of Isolated Individualism, people tend to look away from the disabled and their parents, easing our conscience with token donations. They are often left to seek answers on their own initiative – unless, of course, compassionate neighbors or the helping professions stand by them.

Opportunities for relief can be found: The disabled child can be sent to a 2-week summer camp, giving the family a chance to socialize and the child a chance to learn of wider horizons; a home aide can be arranged to release the parents for monthly parent meetings, and church members may respond to the suggestion to drop in and to pitch in once in a while.

Parents of disabled children experience many types of Persistent Uncertainty. Among these are Differential Diagnosis, Priorities Among Disabilities, and Gaps in Services as well as in Continuity of Care.

"Throughout our country there are thousands of parents who live puzzled years with children who have subtle disabilities. Too often these subtleties are not diagnosed or treated until rejection from school forces the issue. In contrast are thousands who receive specifics early because of the very gross nature of a child's multiple disabilities. Unfortunately, they find little care, since the child fits everywhere, but nowhere," concludes Dr. Robinault.

B. Preparing for Responsible Independence

General – How to Cope with Activities of Daily Living

1. Evaluation at a rehabilitation center to determine your ability.
2. Planning your daily activities and how to cope with specific problems.
3. If help is needed, learning to ask for help is important.
4. Then learning how to give specific directions to a person helping you. This helps to put the person at ease and encourage him to want to be of help.
5. Evaluate your room, house, etc. to determine if necessary accommodations would help you to be more independent.
6. Be aware of the "aids" for independent living, e.g., sliding board, stair glide, lifts, hand controls for driving, ramps, etc.

Results of Activities at Human Resources School

Benefits of the visit of a Rehabilitation Physical Therapist to the Health Classes which had been combined with a peer group from a local high school: We discussed the need for planning for the ADLs. The therapist explained all the problems that the rehabilitation patients at IRM need help with and our students expressed the feelings that they had already adjusted to these things. The non-disabled students could see that our students were well adjusted and have already come a long way. It also gave them an idea of the many problems our students have overcome and that other physically disabled persons had to overcome.

Then two feelings came out about how the non-disabled feel. One predominant feeling is nervousness about helping a disabled person and the fact that if the person tells them what to do they feel more at ease about doing it; that they are willing but not knowledgeable about how to help. Disabled students also had the opportunity to express how they felt (a) when people offer help that is not needed and (b) when people refuse help that is needed. The non-disabled students could see that they would have similar reactions if they were in the same position so that it brought the two sets of students closer together in thinking of each other's way of looking at things.

General – The Homemaking Department of the Institute for Rehabilitation Medicine at Rusk Institute (400 East 34th Street, New York City) teaches ADLs through experience in an adapted house.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
B. Preparing for Responsible Independence **Objective:** Accept responsibility for caring for yourself. It is important to develop skills and knowledge which would allow a disabled person to live as independently as possible.	1. Simulate a plan to move to an apartment in which you will be responsible for yourself. Investigate the costs of living on your own. Make a budget. List sources of income and probable expenses such as rent, utilities, food, clothing, etc. List methods of managing your washing, ironing, cooking, cleaning, shopping. 2. As alternatives in living arrangements other than with your family or in an institution, investigate and discuss: Good-will Apartments run by the V.A. Adapted housing such as Horizon House "Halfway House" – group homes 3. Learn the following practical procedures by doing them or by accompanying someone who is doing them: open a bank account buy life insurance buy auto insurance buy a medical insurance policy buy a car figure your or a relative's income tax.	1. Put your plan into practice in cooperation with the business department in preparing your budget and the homemaking department in learning methods of managing your daily living activities. 2. Invite a guest speaker from a rehabilitation institute who can discuss the practicalities of managing ADL's on your own.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
	4. Invite a disabled alumnus to come to class to discuss the following topics: What can a Health Aide do for a disabled person? (depending on need – can bathe, dress, neaten, cook, shop, prepare meals) How do you get a Health Aide? (apply to Medicaid) How to work to change laws – write Congressmen and Senators, vote, petitions. How to register to vote – overcoming accessibility barriers. How to vote – may be done by absentee ballot.	4. Discuss: Pros and cons of living in one's own apartment – advantages of having a roommate, economy in keeping disabled person in an apartment rather than in a nursing home or institution. Rights of a physically disabled person over 21 years of age (same as non-disabled). Supplemental Security Income Medicaid Other programs
	Conduct simulation workshops: a. Plan a wedding reception. By phone and by car investigate the cost and problems of obtaining an accessible place, planning the menu, hiring musicians, caterers, photographer. Find out about the civil or religious arrangements necessary. Find out about blood tests required by law. b. Plan a party – invite the guests, plan the preparation of the refreshments, plan the decorations, make a budget of all costs. c. Plan a one week vacation. Contact a travel bureau, an airline, train, or bus company, hotels or motels and find out about prices, schedules, accessibility.	1. Make a 5-year plan and a 10-year plan outlining what you would like to accomplish during that time period, things you would have to do, things you would need to learn, how much money you would need to accomplish one particular goal.

BACKGROUND INFORMATION 10, 11, 12

C. Single or Married Adult Life

General – Helpers are usually involved with the physically disabled, and, with proximity and kind treatment, feelings may be confused on both sides: by the helper in not being able to distinguish between pity, love, or the satisfaction of being needed; by the disabled person about whether this is concern or love – and whether he feels love or gratitude for the helper.

The socially limited young adult is also more vulnerable to exploitation.

Enlarged circles of acquaintances and ability to really communicate with others may help the disabled person to form a more mature judgment on the motives of those who seemingly offer friendship. A healthy self-image is also necessary in order to avoid cynicism and achieve a sensible openness to accepting friendship and love.

Method at Rusk – Workshop for disabled and "significant other" – Inundation of explicit sexual films to overcome initial embarrassment at discussing sex, sexual problems and the possible methods of overcoming sexual problems.

Need encouragement to overcome poor body-image and self-image and to think of themselves as lovable people.

When he reaches adulthood the physically disabled person will expect to make his OWN decision to marry, just like other young adults in our society.

The chief difference between disabled and nondisabled children is that the disabled youngster may have much less actual experience in boy-girl social activities and so may be less assured. The best remedy is to increase his social opportunities and make clear the expected standards of behavior. There is no reason to think that a child with a disability is less trustworthy than another.

If he asks you about his future, answer that it will depend on how he feels and how he is making out when he reaches adulthood. There is no need for parents or teachers to pretend to know what in fact they don't know.

As with other aspects of life, the best thing he can do is to work toward the greatest achievable competence through therapy and educational, social, and vocational preparation.

For the teenager a good orientation to the responsibilities of parenthood, head of the family, wage earner is needed including how to run your own home.

Single Life

Don't overlook the fact that many entirely normal persons who are not married live happy, useful lives. Without belaboring the point, you can help an adolescent for whom marriage is not likely by showing that you admire unmarried men and women in the community, and that you don't think of them as "old maids" or "fussy bachelors."

Satisfaction in Marriage

Satisfication is quite different from orgasm. Further, sex is, itself, usually used as a means of communicating deep feelings. These feelings can be provided with simple touches, glances, and personal interchanges, which don't require elaborate gymnastics or idealized anatomy. Satisfaction is most often a result of good sexual communication and shared intimacy and is independent of orgasm. Satisfaction and orgasm may be simultaneously sought after but separately achieved. If we make this idea acceptable, we will have helped them in a major way.

It is also important to emphasize the fact that real love is not based solely on sex and that sexual satisfaction involves intellectual and spiritual as well as physical mating.

If a sexual relationship is not possible one need not automatically rule out the idea of marriage. There are many other rich values in marriage, and these may be sufficient for the disabled person and his spouse. But both must be ready to give more of themselves to compensate.

An important topic is the choice of a partner. The difference between a love-affair and the essentials for a permanent relationship between two people must be discussed; for it is not a matter of making selfish demands, but of looking for the happiness of the other individual and of being ready to share their work and worries.

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
C. Single or Married Adult Life **Objective:** Appreciate your contribution to your future success as a single or married adult.		
1. Preparation for a meaningful life, whether as a single or married person, involves maturity, independence, self-concept, acceptance, and personal adjustment.	1. Present a class discussion on alternate life styles in family living for disabled people. 2. Discuss: What is the role in society for the single person? Can they find happiness in a couple-oriented culture?	1. Explain how familial, cultural, and religious values contribute to a more meaningful adult life.
2. The healthiest motivation for a good marital relationship would be mature love.	1. Invite a school psychologist to lead you in a disucssion comparing love with feelings such as infatuation, gratitude, dependence or loneliness.	
3. Successful marriage depends more on attitudes and abilities than on disability.	1. Tell why the following factors contribute to the success of a marriage: choosing a partner with similar values and attitudes learning consideration of other people learning the difference between mature love and infatuation learning to disagree amiably and constructively exercising responsibility as "head of the house" agreeing on and acting with parental responsibility learning to cope with crises	1. Interview your parents about the problems faced in marriage. Ask them what areas caused the most difficulties and ask their solutions to the problems. 2. Make a directory of resources in your community for premarital and marital counseling services.

BACKGROUND INFORMATION 10, 11, 12

Marriage is a role, a relationship, and a behavior. It requires as a minimum, a degree of independence – both psychological and physical, of support – both psychological and financial, and a certain level of emotional maturity. And our society is geared toward marriage, not only as the major expression of our sexual roles as men and women, but also, within the constraints of our changing sexual mores, as still the only fully acceptable vehicle for sexual behavior.

Parenthood

A severe orthopedic handicap does not prevent a person from being a good parent. Being a parent involves not only the practical care of the child, but also giving it emotional security and love. On the other hand, handicapped parents run into difficulties if no childminding services are available when needed.

Mothers who cannot physically enforce their commands are apt to anticipate problems with discipline. These women find it a great advantage to have some knowledge of child development so they can rely more fully on an understanding of their children's nature. They learned to cope with the problem of outdoor supervision – for example, by keeping a young child within a fenced area they can watch, making their back yard the neighborhood play center by providing interesting play equipment to attract other youngsters. They also succeed in teaching very young children to do much more for themselves than is usual in such matters as washing, bathing, getting ready for bed, or straightening their rooms.

Fortunately, rearing children and managing a happy home do not depend on freedom from disability. The question is much more closely related to the kind of person the mother is. A recent study of more than 100 handicapped mothers showed that many of the most severely disabled were quite effective in guiding the rest of the family in doing the household tasks that they themselves couldn't perform. They still took an active and responsible part in all family decisions. Since they weren't busy doing things themselves, they could give full attention to showing appreciation and maintaining good relations with their husbands and their children. In playing this special role, these mothers were noticeably happy and optimistic.

Divorce

As regards the grounds for divorce, there is no reason to suppose that negative attitudes toward the handicap from the non-handicapped partner were decisive. In some cases, divorce was due to the marriage having been entered hastily, or the non-handicapped person's reason for marriage having been other than love and affection.

BACKGROUND INFORMATION 10, 11, 12

D. Experiences in Child Care

1. Senior boys and girls volunteered their services in both our infant program and pre-school classes for disabled children. Through the coordination of the teachers of child development and the pre-kindergarten and kindergarten teachers, seniors spent three periods a week in Human Resources' pre-school classes learning to help the younger children with their physical and learning needs, and giving the youngsters a sense of identification with young adults. They learned about the needs of young children and about their own ability to fulfill those needs if they have a family.

Beneficial Effects of Family Life Education and Child Development Experiences

1. The opportunity to work with physically disabled pre-school children taught our seniors certain basic understandings about caring for disabled children such as:
   - the importance of movement to the child's physical growth and development
   - the importance of play to induce the children to move
   - that providing encouragement for communication can help children to develop language skills
   - enriched opportunities can overcome experience deprivation in early years.

The program benefited the young children in two ways:

1. It improved the self-concept of the little children because a senior cared about them and played with them.

2. It improved their own expectations for the future when they saw the disabled seniors helping them and the teacher, and talking about their own independence.

The program benefited the seniors in three ways:

1. It improved the seniors' own self-image because the young children looked up to and admired them, and it gave them an opportunity to be of service to others.

2. It gave the seniors more realistic expectations about their own abilities to care for a disabled (or able-bodied) child.

3. By participating in the infant program, the seniors had an opportunity to observe how mothers can care for and enjoy their disabled babies.

Early Intervention Programs

An early intervention school program can provide emotional, social and skills development experiences which physically handicapped infants often missed because both home and hospital were concentrating on caring for their physical needs.

280

CONCEPTS	STUDENT ACTIVITIES	STUDENT SELF-EVALUATIONS
D. Experiences in Child Care **Objective:** Learn to care for a child's needs and activities. A supervised experience in caring for a young child's needs can give a realistic understanding of one's ability to cope with future responsibility.	1. In coordination with the Home Ec and Health Ed teachers develop a program of volunteer teacher-aides in a Pre-K or K class. Plan with your teachers and the Pre-K teachers, your exact duties and learn exactly how you should help and what you should avoid doing. Make notes on special precautions. Visit or write to a school which has an early childhood education intervention program. Then explain the purposes of the infant program of early education for disabled babies to your classmates.	1. Keep a log of your observations on children's behavior and abilities at each age. 2. Compare your findings with those of your classmates at your weekly seminar. Inquire what facilities are in your community for babies with birth defects.

Appendix

The following are the topics covered in the New York State Curriculum (see ERIC # ED070994) and recommended as a starting point for all physically disabled students.

MENTAL HEALTH
K-3

1. The Family
   - A. The basic family
   - B. Family similarities and differences
   - C. Functions of the family
     1. Transmits culture
     2. Educates the young
     3. Provides food, clothing, shelter
     4. Provides identification for members
     5. Provides understanding and love
        - a. Expression of love
        - b. Self-understanding
        - c. Understanding others
     6. Provides recreation and other activities
   - D. Roles of family members
     1. Father's role
     2. Mother's role
     3. Children's role

II. Understanding the Life Cycle
   - A. Male and female gender
   - B. Meaning of reproduction
   - C. Preparing for the new baby
     1. Importance
     2. Role of parents
   - D. Meeting the needs of the newborn
     1. Parents' role
     2. Child's role in caring for the new brother or sister

III Human Growth and Development
   - A. Physical
   - B. Mental
   - C. Social
   - D. Emotional

MENTAL HEALTH
4-6

I. Family as a Social Unit
   - A. Family groups
     1. Nuclear families
     2. Extended families
     3. Adoptions
     4. Foster homes
   - B. The role of the family in the community
   - C. Family dynamics
     1. Government in the family
     2. Communication in the nuclear family
     3. Variations in family patterns
     4. Family activities
     5. Health of family members
   - D. Differences of cultural heritage

II. Role arrangements in Family Life
   - A. Maleness and Femaleness
     1. Heredity
     2. Environment
     3. Learning sex roles
   - B. Role flexibility
   - C. Human reproduction
     1. Importance of the family
     2. Role of parents
     3. Conception and development of the new baby
        - a. Conception
        - b. Gestation
     4. The miracle of childbirth
     5. Multiple births

III. Personality
   - A. Conception of personality
     1. Definition
     2. Healthy personality
   - B. Development of personality
     1. Influence of environment

2. Influence of heredity
   a. Body structure
   b. Physical features
   c. Intelligence
   d. Sensory perception
   e. Rate of physical growth
   f. Sex

C. What characteristics are not inherited
   1. Traits
   2. Specific traits

D. Basic human needs
   1. Physiological needs
   2. Psycho-social needs
      a. Psychological needs
      b. The need for love
      c. The need for approval
      d. The need for independence
      e. The need to feel significant

IV. Growing Toward the Teen Years
   A. Development of the physical self
      1. Major growth periods
         a. Infancy and early childhood
         b. Middle and late childhood
         c. Puberty and adolescence
            (1) Growth rate of boys and girls
            (2) Appearance of secondary sexual characteristics
            (3) Menarche
            (4) Changes in the skin and hair
      2. Attitudes toward the physically developing self
   B. The developing social self
      1. The individual and the group
      2. Peer relationships
      3. Sexual differences in social development
      4. Relationships within the family
         a. Relationships with parents
         b. Sibling relationships
   C. Emotional development
      1. The nature of emotion
      2. Commonality of emotions
      3. Origin of emotions
      4. Emotional expressions
         a. Positive release of feeling
         b. Negative or self-defeating responses
      5. Effect of emotions on the body

MENTAL HEALTH
7-9

I. Why We Do the Things We Do
   A. Basic needs
      1. Physical needs
         a. Food and Water
         b. Shelter
         c. Protection from elements
      2. Emotional needs
         a. Love
         b. Security
            c. Recognition – the feeling of personal worth and achievement
         d. Competence – the feeling of personal achievement and worth
         e. Independence
         f. Self-actualization
   B. Success in getting what we need
   C. Frustration
   D. Reactions to frustration
      1. Disruptive effects
      2. Constructive effects

II. Learning More About Ourselves
   A. Growing and Developing
      1. Nature of development
      2. Adolescent development
         a. Achieving new and more mature relations with peers of both sexes
         b. Achieving a masculine or feminine social role
         c. Accepting one's physical appearance and using the body effectively
            1. Sexual changes

2. Effect of these changes on sexual roles
d. Achieving emotional independence of parents and adults
e. Achieving assurance of economic independence
f. Selecting and preparing for an occupation
g. Preparing for marriage and family life
h. Developing civic competence
i. Desiring and achieving socially responsible behavior
j. Acquiring a set of values and an ethical system as a guide to behavior

III. Dimensions of Maturity
A. Physical maturity
1. Maturation of the reproductive system
2. Skeletal growth
3. Uniqueness of individual growth patterns
B. Relationships to other maturities
1. Adult appearance and immature behavior
a. *Looking* "grown up" is not *being* "grown up"
b. Conflicts within the family
1. Parent and child
2. Sibling relationships
c. Privileges of maturity mean increased responsibility
C. Emotional maturity
1. Growth in understanding
2. Growth in tolerance
3. Growth in acceptance
4. Growth in respect
5. Growth of the social self
6. Acceptance or rejection of others
a. Prejudging others
b. "Halo effect" and reactions to others
c. Prejudice and non-acceptance
7. Relationships with others
a. Concern for the welfare and dignity of others
b. The nature of friendship
c. Leadership and followership

IV. Boy-Girl Relationships During Adolescence
A. The emerging self
1. Discovering physical changes

a. External changes
b. Internal changes
2. Discovering emotional changes
a. New urges and feelings (moods)
b. Emotional responses
3. Changing values and interests
4. Awareness of personal uniqueness
5. Accepting the self with pride and responsibility
a. Physical changes
b. Mental and emotional changes
c. Social changes
B. Dating patterns
1. Factors influencing dating behavior
a. Family influence
b. Peer pressure
c. Mass media
d. Stage of mental and physical development
2. Types of dates
a. Single
b. Double
c. Group
d. Blind
3. Disadvantages of early dating
4. Skills developed by dating
5. Dating considerations
a. Choosing, asking for, accepting or refusing a date
b. Dating activities and etiquette
6. Dating issues, problems, and special concerns
7. Intimate behavior

The following are the topics covered in the New York State Curriculum and recommended as a starting point for all physically disabled students. This section has not yet been printed.

STRAND III

Personality Development Grades 10, 11, 12

I. Mental and Emotional Health
- A. Theories of personality
- B. Personality development
- C. Adjustment and mental health
- D. Levels of personality organization
- E. The individual's role in the group
- F. Mental health as related to life areas
- G. Mental health and the developing individual

II. Motivation in Human Behavior
- A. Goal-directed behavior
- B. Biological drives
- C. Psychological motivation
- D. Motivation of others

III. Mechanisms in Adjustment
- A. Defensive behavior patterns
- B. Classification of adjustment patterns
- C. Defense mechanisms

IV. Mental Disorders
- A. Definition
- B. Symptoms
- C. Types and classifications
- D. Misconceptions about mental illness
- E. Extent of mental illness
- F. Treatment of mental disorders
- G. Mental retardation

V. Mental Health Services
- A. The mental hospital
- B. The semihospital
- C. Residential facilities
- D. The sheltered workshop
- E. The social club
- F. The community mental health center
- G. The National Association for Mental Health
- H. Government agencies
- I. Child guidance clinics
- J. Some workers in improvement

VI. Current Research
- A. Mental health in education
- B. Innovations in school mental health programs
- C. Utilization of mental health professionals in the school
- D. Psychology and cultural determinants of behavior
- E. The concept of ego development

Sexuality and Family Life Education

I. Human Growth and Development
- A. Personality
- B. Human Sexuality – role perception

II. Human Relationships
- A. Dating
- B. Love
- C. Premarital relationships
- D. Values and goals

III. Marriage
- A. Criteria for marital success
- B. Marriage relationship
- C. Marital compatability and growth
- D. Marriage laws
- E. Marriage as a contract
- F. Unmarried adults

IV. Teenage Marriages
- A. Arguments – pro
- B. Arguments – con

V. Responsible Sexuality
- A. Familial and societal responsibility
- B. Individual

VI. Human Reproduction
- A. Prenatal Care
- B. Gestation

HELPFUL TEACHER REFERENCES USED BY HEALTH PROJECT COMMITTEE

MENTAL HEALTH

Ayrault, Evelyn West. Helping the Handicapped Teenager Mature. New York: Association Press, 1971.

Ayrault, Evelyn West. You Can Raise Your Handicapped Child. New York: G. P. Putnam's Sons, 1964.

Cobb, A. Beatrix. Medical and Psychological Aspects of Disability. Springfield, Illinois: Charles C. Thomas, 1973.

Connor, Frances P.; Wald, Joan R.; Cohen, Michael J. Professional Preparation for Educators of Crippled Children. New York: Teachers College, Columbia University: 1970.

Cruickshank, William, Ed. Psychology of Exceptional Children and Youth. Englewood Cliffs, New Jersey: Prentice-Hall, Inc., 1971.

Easson, William M. The Dying Child – The Management of the Child or Adolescent Who Is Dying. Springfield, Illinois: Charles C. Thomas, 1970.

Easson, William M. Management of the Dying Child. Journal of Clinical Psychology. Summer 1974. p. 25-27.

Ellis, Albert. Guide to Rational Living.

Farkas, Andrea. Research on Families of Terminally Ill Children: Problems and Reward. Journal of Clinical Psychology. Summer 1974. p. 41-43.

Heisler, Verda. A Handicapped Child in the Family – A Guide to Parents. New York: Grune and Stratton, 1972.

Kastenbaum, Robert. Childhood: The Kingdom Where Creatures Die. Journal of Clinical Psychology. Summer 1974. p. 11-14.

Krusen, Frank H.; Kottke, Fredric J.; Ellwood, Paul M. Handbook of Physical Medicine and Rehabilitation. Philadelphia: W. B. Saunders, 1971.

Kubler-Ross, Elizabeth. The Languages of Dying. Journal of Clinical Psychology. Summer 1974. p. 22-24.

Leviton, Dan; Forman, Eileen Cleiman. Death Education for Children and Youth. Journal of Clinical Psychology. Summer 1974. p. 8-10.

Lifton, Robert Jay; Olson, Eric. Living and Dying. New York: Praeger Publishers, 1974.

Nagy, M. The Child's View of Death (1948). Reprinted in H. Feifel (ed.). The Meaning of Death. New York: McGraw-Hill. p. 79-98.

Neff, Walter S. Ed. Rehabilitation Psychology – Proceedings of the National Conference on the Psychological Aspects of Disability. Washington, D.C.: American Psychological Association, Inc., 1971. (See Chapter 2 – Physical Disability and Personality. p. 33-73, by Franklin C. Shontz.)

Robinault, Isabel P. Feedback from the Family of Man: Guidance Pointers from Parents of Disabled Children. Rehabilitation Literature. Aug., 1968, Vol 29, No. 8, p. 226-232, 236.

Safilios-Rothschild, Constantina. The Sociology and Social Psychology of Disability and Rehabilitation. New York: Random House, 1970.

Schnell, Richard. Helping Parents Cope with the Dying Child with a Genetic Disorder. Journal of Clinical Psychology. Summer 1974. p. 34-35.

Spock, Benjamin; Lerrigo, Marion O. Caring for Your Disabled Child. New York: Macmillan Co., 1965.

Swets, John A.; Elliot Lois L. Eds. Psychology and the Handicapped Child. Washington, D.C.: U.S. Department of Health, Education, and Welfare, Office of Education, 1974.

Tritell, Anita. Financial Assistance for the Disabled. Albertson, New York: INA-MEND Institute – Human Resources Center, 1975.

Tritell, Anita. General Information to Help the Recently Disabled. Albertson, New York: INA-MEND Institute – Human Resources Center, 1974.

Tritell, Anita. The Rehabilitation Facility and Its Specialists. Albertson, New York: INA-MEND Institute – Human Resources Center, 1975.

Vernon, David T. A.; Foley, Jeanne; Spiowicz, Raymond; Schulman, Jerome. The Psychological Responses of Children to Hospitalization and Illness. Springfield, Illinois: C. C. Thomas, 1965.

Waldhorn, Hilda. Rehabilitation of the Physically Handicapped Adolescent. New York: The John Day Company, 1973.

Willis, Diane, I. The Families of Terminally Ill Children: Symptomatology and Management. Journal of Clinical Psychology. Summer 1974, p. 32-34.

Wright, Beatrice. Physical Disability – A Psychological Approach. New York: Harper and Row, 1960.

Wright, Logan. An Emotional Support Program for Parents of Dying Children. Journal of Clinical Psychology. Summer 1974. p. 37-38.

Wysock, B. Body Image of Crippled Children as Seen in Draw-a-Person Test Behavior. Perceptual and Motor Skills, 1965. p. 21, 499-504.

ATTITUDES

Barron, David. Coping with the Stereotype of the Handicapped. Journal of Rehabilitation. March-April, 1967, Vol 33 No. 2.

Braun, Carl; Neilsen, Allen R.; Dykstra, Robert. Teacher's Expectations: Prime Mover or Inhibitor? Elementary School Journal. Dec., 1975.

Cochran, Caryl L. A Question of Motivation. Pointer, Winter 1972, Vol. 17, No. 2, p. 146-148.

Combs, Ronald H., and Harper, Jerry L. Effects of Labels on Attitudes of Educators Toward Handicapped Children. Exceptional Children, February, 1967, p. 399-403.

Eiseman, Russell. Attitudes Toward the Physically Disabled: Report on a Research Program, With Implications For Psychotheraphy.

Hogson, Frank M. Special Education – Facts and Attitudes. Exceptional Children. January, 1964.

Jaffe, Jacob. What's in a Name – Attitudes Toward Disabled Persons. Personnel and Guidance Journal, February, 1967, p. 557-560.

Krusen, Frank H.; Kottke, Frederic J.; Ellwood, Paul M. Handbook of Physical Medicine and Rehabilitation. Philadelphia: W. B. Saunders, 1971.

Linkowski, Donald C. A Scale to Measure Acceptance of Disability. Rehabilitation Counseling Bulletin. June, 1971.

Linkowski, Donald; Dunn, Marilyn. Self-Concept and Acceptance of Disability. Rehabilitation Counseling Bulletin. September, 1974. p. 28-32.

Lippman, Leopold D. Attitudes Toward the Handicapped – A Comparison Between Europe and the United States. Springfield, Illinois: Charles C. Thomas, 1972.

Lynch, Denis J. and Arndt, Charles. Developmental Changes in Response to Frustration Among Physically Handicapped Children. Journal of Personality Assessment. April 1933, No. 2, p. 230-135.

National Easter Seal Society for Crippled Children and Adults. When You Meet a Handicapped Person . . . Fifteen Hints for Rewarding Relationships. Chicago: author, 1967. (pamphlets)

Rapier, Jacqueline; Adelson, Ruth; Carey, Richard; Croke, Kathrine. Changes in Children's Attitudes Toward the Physically Handicapped. Exceptional Children: November, 1972, p. 219-223.

Richardson, Stephen A.; Hastof, Albert H.; Dornbusch, Sanford M. Effects of Physical Disability on a Child's Description of Himself. Child Development, 1964, Vol. 35, No. 3, p. 893-907.

Roher, G. Allan. Significance of Public Attitudes in the Rehabilitation of the Disabled. Rehabilitation Literature: March, 1961, Vol. 22, No. 3, p. 66-72.

Rusk, Howard A. Disabled Students – Barriers of Discrimination Are Being Eliminated in Universities and Colleges. New York Times. Sept. 24, 1961.

Schoggen, Phil. Observed Behavior of Mothers and Teachers Toward Children with Physical Disabilities in Natural Situations. George Peabody College for Teachers. Unpublished report. n.d.

Schroeder, Clifford E. Accepting the Handicapped Pupil. Nursing Outlook, May, 1963, Vol. 11, No. 5.

Vincent, Raymond J. New Scale for Measuring Attitudes. School Health Review, AAHPER, 1974, p. 19-21.

Wright, Beatrice A. Disabling Myths about Disability. Chicago, Illinois: National Easter Seal Society for Crippled Children and Adults, 1961.

Yuker, Harold E. ATTITUDES as Determinants of Behavior. Journal of Rehabilitation, 1965, Vol. 31, No. 6, p. 15-16.

Yuker, Harold E.; Block, J. R.; Younng, Janet H. The Measurement of Attitudes Toward Disabled Persons – Human Resources Study #7. Albertson, New York: Human Resources Center, 1966.

Yuker, Harold E.; Block, J. R.; Younng, Janet H. The Measurement of Attitudes Toward Disabled Persons. Albertson, New York: INA-MEND Institute, 1970.

Zweig, Linda; Ensor, Phyllis; Patti, Anthony. Birth Defects and Attitudes Toward Children – Special Health Education Unit. White Plains, New York: The National Foundation, Division of Health Information. n.d

SEX EDUCATION

Balester, Raymond J. Sex Education: Fact and Fancy. The Journal of Special Education, 1971, Vol. 5, No. 4, p. 355-357.

Berkman, Anne H. Sexuality: A Human Condition. Journal of Rehabilitation, Jan.-Feb. 1975. p. 13-15, 37.

Berthiaume, Laurie. What the Human Body Looks Like, and How the Human Body Works. Howard Tolonen, Director of Special Services, 1018 South 1st Street, Stillwater, Minnesota 55082.

Bidgood, Frederick. Sexuality and the Handicapped. SIECUS Report, Jan. 1974, Vol. II, No. 3.

Blom, Gaston D. Some Considerations about Neglect of Sex Education in Special Education. The Journal of Special Education, 1971, Vol. 5, No. 4, p. 363-364.

Bloom, Jena L. Sex Education for Handicapped Adolescents. The Journal of School Health, 1969, p. 363-367.

Burt, John J.; Meeks, Linda Bower. Toward a Healthy Sexuality. Philadelphia: W. B. Saunders, 1973.

Chigier, E. Sexual Adjustment of the Handicapped. Paper presented to Twelfth World Congress of Rehabilitation International. 1971.

Comarr, A. Estin; Gunderson, Bernice B. Sexual Function in Traumatic Paraplegia and Quadriplegia, American Journal of Nursing, Feb. 1975, Vol. 75, No. 2, p. 250-255.

Committee on Health Guidance in Sex Education. Growth Patterns and Sex Education. A Suggested Program for Kindergarten through Grade Twelve. Kent, Ohio: American School Health Association, 1974.

Delp, Harold A. Sex Education for the Handicapped. The Journal of Special Education., Vol. 5, No. 4, 1971, p. 359-361.

Diamond, Milton. Sexuality and the Handicapped. Rehabilitation Literature. Feb. 1974, Vol. 35, No. 2, p. 34-40.

Friedman, Erwin. Missing in the Life of the Retarded Individual – Sex: Reflection on Sol Gordon's Paper. The Journal of Special Education, 1971, Vol. 5, No. 4, p. 365-368.

Gordon, Sol. Facts About Sex for Today's Youth. New York: John Day Co., 1973. (Paperback)

Gordon, Sol. Facts About V.D. – A Basic Guide for Teenagers. New York: John Day Co., 1973. (Paperback)

Gordon, Sol. Missing in Special Education: Sex. The Journal of Special Education. 1971. Vol. 5, No. 4, p. 351-354.

Gordon, Sol. Okay Let's Tell It Like It Is (Instead of Just Making It Look Good.) The Journal of Special Education. 1971, Vol. 5, No. 4, p. 379-381.

Gordon, Sol. The Sexual Adolescent – Communicating with Teenagers about Sex. Belmont, California: Wadsworth Publishing Company, Inc., 1973.

Griffith, Ernest; Trieschman, Roberta; Hohmann, George; Cole, Theodore; Tobis, Jerome; Cummings, Victor. Sexual Dysfunction Associated with Physical Disabilities. Archives of Physical Medicine and Rehabilitation. Jan. 1975, Vol. 56.

Griffith, Ernest; Trieschmann, Roberta. Sexual Functioning in Women with Spinal Cord Injury. Archives of Physical Medicine and Rehabilitation. Jan. 1975, Vol. 56.

Gregory, Martha Ferguson. Sexual Adjustment – A Guide for the Spinal Cord Injured. Bloomington, Illinois: Accent on Living, Inc., 1974.

Gundale, Marlene. "Menstrual Hygiene. Howard Tolonen, Director of Special Services, 1018 South 1st Street, Stillwater, Minnesota 55082.

Held, James P.; Cole, Theodore M.; Held, Constance A.; Anderson, Carol; Chilgren, Richard A. Sexual Attitude Reassessment Workshops. Effects on Spinal Cord Injured Adults, Their Partners and Rehabilitation Professionals. Archives of Physical Medicine and Rehabilitation. Jan. 1975, Vol. 56, p. 14-18.

Heslinga, D. Not Made of Stone – The Sexual Problems of Handicapped People. Springfield, Illinois: Charles C. Thomas, 1974.

Kirby, Alan R. Sexual Function in the Spinal Cord Injured Person. n.d.

Lassen, Peter. Sex and The Spinal Cord Injured – A Selected Bibliography. Washington, D.C.: Paralyzed Veterans of America, 1973.

Money, John. Special Sex Education and Cultural Anthropology, with Reference to Mental Deficiency, Physical Deformity, and Urban Ghettos. The Journal of Special Education. 1971. Vol. 5, No. 4, p. 369-372.

Nordquist, Inger, compiler. Life Together – The Situation of the Handicapped. Stockholm: E. Olofssons Boktryckeri A. B, 1972.

Reich, Melvyn L.; Harshman, Hardwich W. Sex Education for Handicapped Children: Reality or Repression? The Journal of Special Education. 1971. Vol. 5, No. 4, p. 373-377.

Schulz, Esther; Williams, Sally R. Family Life and Sex Education: Curriculum and Instruction. New York: Harcourt, Brace, and World, Inc., 1969.

Singh, Silas P.; Manager, Tom. Sex and Self – The Spinal Cord Injured. Rehabilitation Literature, 1975, Vol. 36, No. 1, p. 2-10.

Smith, Jim; Bullough, Bonnie. Sexuality and the Severely Disabled Person. American Journal of Nursing. Dec., 1975, p. 2194-2197.

Vance, Frank, Project Director. Social and Sexual Development. A Guide for Teachers of the Handicapped. The Iowa State Department of Public Instruction and the University of Iowa: Special Curriculum Development Center, 1971.

ANNOTATED BIBLIOGRAPHY FOR SPECIFIC DISABILITIES (continued)

DYSAUTONOMIA (continued)

with teachers, parents' role in schooling, and different types of schools.

Riley, C. M. Living With A Child With Familial Dysautonomia. Brooklyn, New York (32 Court St.): Dysautonomia Association, 1956, 40 pages.

Detailed information for parents of dysautonomic children. Coverage includes a description of the autonomic nervous system as it is affected by the condition, management of dysautonomic children, heredity, genetics, and research.

HEART DISEASE

American Heart Association. Children With Heart Disease: A Guide for Teachers. Mineola, New York (365 Willis Ave.): Author, 1971, 15 pages.

Presents a general description of the symptoms, hospitalizations, and treatments faced by children with rheumatic fever or congenital heart defects. Suggests practical ways of dealing with absences and the question of vocational counseling. Gives sources of help for medical services and includes a bibliography of teaching aids.

HEMOPHILIA

National Hemophilia Foundation. The Hemophiliac and His School. New York (25 W. 39 St.): Author, n.d. 7 pages.

A source of information for school personnel who deal with Hemophiliac children. Coverage includes symptoms, prevention of injury, and treatment in emergencies. Suggests local NHF chapters as sources of additional information.

National Hemophilia Foundation. New Perspective on Hemophilia. New York (25 W. 39 St.): Author, n.d. 6 pages.

HEMOPHILIA (continued)

Brief coverage of the symptoms and genetic pattern of inheritance of hemophilia, the latter shown traced through British royalty. Description of the work done by the National Hemophilia Foundation.

National Hemophilia Foundation. Psychological Aspects of Hemophilia. New York (25 W. 39 St.): Author, n.d. 14 pages.

Presentation of the problems of overprotection, bleeding and emotions, adaptation, risk from action, maturity, discipline, hospitalizations, treatments, and family relations. Includes a bibliography for additional information.

Vogel, James M. How to Live With Hemophilia. New York: Interbook Incorporated, n.d.

Written by a physican to explain details to be considered in the activities of daily living of the hemophiliac. Contains clear explanation of the blood factors involved and of the hereditary aspects of the disease.

KUGELBERG-WELANDER DISEASE

Muscular Dystrophy Associations of America. Kugelberg-Welander Disease or Juvenile Spinal Atrophy Fact Sheet. New York (1970 Broadway): Author, n.d. 3 pages.

Brief information on Kugelberg-Welander disease, presented in the same format as the MDAA fact sheets on Amyotonia Congenita. Offers local MDAA offices as sources of additional information.

MUSCULAR DYSTROPHY

Muscular Dystrophy Associations of America. Muscular Dystrophy Fact Sheet. New York (1970 Broadway): Author, n.d. 3 pages.

ANNOTATED BIBLIOGRAPHY FOR SPECIFIC DISABILITIES

AMYOTONIA CONGENITA

Muscular Dystrophy Associations of America. Oppenheim's Disease or Benign Congenital Hypotonia Fact Sheet. New York (1970 Broadway): Author, n.d. 3 pages.

Brief description of the causes, symptoms, inheritance pattern, and progression of Oppenheim's disease, which causes the muscle weakness known as the amyotonia congenita syndrome. Covers medical treatments and research. Offers local MDAA offices as sources of additional information.

Muscular Dystrophy Associations of America. Werding-Hoffman Disease or Infantile Spinal Muscular Atrophy Fact Sheet. New York (1970 Broadway): Author, n.d. 3 pages.

Same format as the MDAA fact sheet on Oppenheim's Disease. General information on Werding-Hoffman disease, which also causes the amyotonia syndrome. Offers local MDAA offices as sources of additional information.

ARTHRITIS

U.S. Department of Health Education, and Welfare. Arthritis. Washington, D.C.: U.S. Government Printing Office, 1968. 6 pages. $ .05 per single copy.

Brief historical description of research and treatment related to rheumatoid arthritis, osteoarthritis, and gout. General information on causes and symptoms of the disease. Includes sources of additional information.

BIRTH DEFECTS

National Foundation – March of Dimes. Birth Defects. White Plains, New York (P.O. Box 2000): Author, n.d. 14 pages.

Simple statistical information on the prevalence of common birth defects in the United States and on those which appear after birth. Description of hereditary and environmental influences, prevention, and treatment.

CEREBRAL PALSY or SPASTIC PARAPLEGIA

Seaver, Jacqueline. Cerebral Paley – More Hope Than Ever. New York (381 Park Ave.): Public Affairs Committee, 1969. Pamphlet # 401. 27 pages. $ .25 per single copy.

General information on the causes and symptoms of cerebral palsy. Covers special problems related to the disability, child development, and employment. Describes treatment and research.

United Cerebral Palsy Associations. Realistic Educational Planning for Children With Cerebral Palsy. New York (66 E. 34 St.): Author, n.d. 24 pages. & .25 per single copy.

A source of information and guidance for school personnel involved in the psychological evaluation of cerebral palsied children. Coverage includes problems in the administration and interpretation of standardized tests. A bibliography of suggested reading is included.

CHARCOT-MARIE-TOOTH DISEASE

Muscular Dystrophy Associations of America. Charcot-Marie-Tooth Disease or Peroneal Muscular Atrophy Fact Sheet. New York (1970 Broadway): Author, n.d. 3 pages.

Brief information on Charcot-Marie-Tooth disease, presented in the same format as the MDAA fact sheets on amyotonia congenita. Offers local MDAA offices as sources of additional information.

DYSAUTONOMIA

Dysautonomia Association. Educating the Child With Familial Dysautonomia. Brooklyn, New York (32 Court St.): Author, 1967, 15 pages.

A practical guide to help parents deal with the educational lives of their dysautonomic children. Includes information on testing, expectations, relations

ANNOTATED BIBLIOGRAPHY FOR SPECIFIC DISABILITIES (continued)

MUSCULAR DYSTROPHY (continued)

Brief information on Muscular Dystrophy, presented in the same manner as the MDAA fact sheet on Amyotonia Congenita. Offers local MDAA offices as sources of additional information.

Muscular Dystrophy Associations of America. Patient and Community Services Program. New York (1970 Broadway): Author, 1973, 19 pages.

Detailed description of MDAA services such as testing and diagnosis, therapy, innoculations, transportation, and recreation. Lists services authorized for payment and criteria for eligibility. Includes a listing of MDAA clinics throughout the United States.

PARAPLEGIA

Bundy, Kathryn. What You Should Know About Paraplegia. Adapted from "An Introduction to Paraplegia" by William H. Edward. Washington, D.C.: U.S. Government Printing Office, n.d. 12 pages. S .25 per single copy.

Written as a practical guide to the new life faced by a paraplegic adult, but presents information valuable to teachers or parents as well. Deals with problems like toileting, skin sores, care of feet, rehabilitation, and sex.

SPINA BIFIDA

Swinyard, C. The Child With Spina Bifida. New York (345 E. 46 St.): Association for the Aid of Crippled Children, 1971. 20 pages.

A general guide for parents, presenting symptoms, causes, treatments, and special problems. Includes clear, simple illustrations. Gives addresses for obtaining translations in nine languages.

SPINA BIFIDA (continued)

Bruce, Margaret, & Veigh, Gretchen. A Practical Guide for Parents of Children With Myelomeningocele. Pittsburgh, Pennsylvania: Allegheny County Easter Seal Society for Crippled Children and Adults, 1972. 32 pages. $2.00 per single copy. *NOTE:* Order directly from Gretchen Veigh, 1065 Findley Dr. E., Pittsburgh, Pa.

A detailed treatment of spina bifida, including numerous topics such as brace adjustment, diet, clothing, medications, exercises, education, and family relations. Illustrated with clear sketches. Included is a glossary of medical terms.